

# HEMOPHILIA WORLD

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**WFH**

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

WFH 2016 World Congress brings the latest scientific developments to the global bleeding disorders community



# The WFH 2016 World Congress makes an impact

The WFH 2016 World Congress held this past July was a great success, welcoming a record 5,482 attendees from 137 countries. The event marked the first Congress in the U.S.A. in over 25 years.

The largest international meeting for the global bleeding disorders community was hosted at the Orange County Convention Center (OCCC), and the venue was an excellent fit for the needs of the WFH World Congress. The exhibit hall was well located so that attendees were never more than a few minutes' walk from a session. All official Congress hotels were also very close to the OCCC, which helped to make the Congress experience that much more convenient for attendees.

As with previous congresses, the WFH 2016 World Congress featured in-depth scientific content, inspiring patient stories and an entertaining social program. "We offer attendees a rich mix of experiences," explained WFH President Alain Weill. "People come to learn about the latest scientific developments for inherited bleeding disorders, but also to connect with community members and build a support network that will last a lifetime."

The medical program featured sessions on all of the hot topics trending in the world of bleeding disorders, including a look at the extended half-life factor products, innovations in immune tolerance induction for hemophilia, management of inhibitors, gene therapy, genomic approaches to bleeding disorders, and developments in the understanding of inhibitors. The multidisciplinary program

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covered an equally large number of topics, such as patient care, new extended half-life products, women with hemophilia, the impact of prophylaxis on children, an update on the effect of Hepatitis C on patients with hemophilia, and aging with hemophilia. A number of the events were eligible for CME or CEU accreditation.

Many patients were at the Congress to share their stories about managing and living with a bleeding disorder and many family members were also there to share their own perspectives. Jeanne White-Ginder told her own story about being a spokesperson for people with AIDS. Kari Atkinson talked about what it was like for her family when her son Beau was diagnosed with hemophilia and an inhibitor. And

Gerard O'Reilly spoke of his experience with hemophilia and Hepatitis C.

The social program was another highlight at the Congress. The Opening Ceremony followed a new panel style discussion where NHF Chair of the Board Jorge de la Riva, WFH President Alain Weill, WFH CEO Alain Baumann, and Val Bias, CEO of NHF, discussed their shared goal of supporting people with bleeding disorders. On the Tuesday, hundreds of people attended the Host Country Networking Reception at the World ShowPlace Pavilion at Epcot®. The evening featured fine dining, dancing and, of course, a totally unexpected visit by Mickey, Minnie, Donald, and Pluto.

The WFH 2016 World Congress would not have been possible without the generosity of a dedicated team of volunteers. This year, 80 of those volunteers were NHF staff and staff from the local NHF Florida Chapter who lent a helping hand to our Congress right after the conclusion of NHF's 68th Annual Meeting.

The WFH would like to thank all attendees, sponsors, and NHF for their support. After another successful Congress, we hope to see all of you in Glasgow in 2018.



# HEMOPHILIA WORLD

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# WFH President: Education is the other side of the Treatment for All equation

In 1942, *The Little Prince* author Antoine de Saint Exupery wrote to a friend: "Far from hurting you, being different enriches you."

Nearly 75 years later, it's still important for everyone in the bleeding disorders community to reflect on that truism, said Alain Weill, WFH president, during the 2016 WFH World Congress plenary "Treatment for All: Another Side of the Equation."

While much has been accomplished in bleeding disorders awareness and treatment, Weill said much remains to be done.

Recent accomplishments include the expansion of the WFH Humanitarian Aid Program. Between 1996, when the WFH started the program, and 2011, the yearly average volume of international units (IUs) of clotting factor donated to developing countries was 10.5 million. Between 2012 and 2014, factor donations increased to 25.5 million IUs per year, and they skyrocketed to 116 million IUs during the last 12 months.

Along with providing more treatment options, Weill said that another objective is to use the WFH Humanitarian Aid Program as leverage to demonstrate to government officials how proper treatment enables people with hemophilia to live a normal life and actively participate in the social and economic activities of their country.

This is crucial because too many people in the global hemophilia community still face frustration, discrimination, and intolerance. "This inequity drives my passion for continued advocacy," Weill said. "We must eliminate the stigma associated with having a bleeding disorder and we should not accept anything else."

Even in developed countries, it can feel like society is at odds with people with bleeding disorders and their families, Weill said. Factor costs can be prohibitive. Employment opportunities can be limited. In some countries, a person with a disability can't get a bank loan. And in numerous countries, it's not unusual for people with hemophilia to be denied services from fearful care providers.

Children with bleeding disorders continue to face discrimination, Weill said. In a significant



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"For when we educate people to see that being a patient of a rare bleeding disorder does not define who that individual is, and instead see them as an active member of society who enriches their community, we will show that it is indeed true that the highest result of education is tolerance."  
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amount of countries, when a child is diagnosed with a bleeding disorder, many families experience devastating hardships. In some cases, when a child with hemophilia reaches school age, some misguided teachers believe bleeding disorders are communicable and ban the child from their classroom. Some parents don't want their children to play with children with bleeding disorders for fear their child may become "afflicted," Weill said. "Already having to deal with their clotting deficiency, many children find themselves confronted with anxiety, depression, and isolation."

But there are steps members of the bleeding disorders community can take to fight this discrimination and intolerance. One way is to educate government and other leaders of existing legislation and regulations protecting

people with disabilities. These include the Universal Declaration of Human Rights Article 1, adopted in 1948, and the United Nations Convention on the Rights of Persons with Disabilities, which was approved in 2006.

In addition, the WHF has recently committed to the WFH Transform 2016 action plan, which increases the number of regional program managers around the world to assess discriminatory situations and offer solutions.

The WFH will also become a member of Rare Diseases International, which has the prime objective of convincing the United Nations to make rare diseases an international health priority.

Weill urged each member of the bleeding disorders community to also think locally when it comes to education. "As you go through the Congress experience, gather the tools that you can take back to your own communities that can help to educate and make a difference," he said.

"For when we educate people to see that being a patient of a rare bleeding disorder does not define who that individual is, and instead see them as an active member of society who enriches their community, we will show that it is indeed true that the highest result of education is tolerance."

# WFH Vice President Medical: The future of hemophilia treatment is very promising

Hemophilia treatment has entered an exciting era, with new products making diagnosis and treatment available for a far larger population than ever before, said WHF Vice President Medical Marijke van den Berg, MD, during her VP Medical Plenary address at the WFH 2016 World Congress.

The session covered a variety of studies in people with severe hemophilia A that demonstrate how early prophylaxis can prevent bleeding and is key for a more positive joint outcome. In these models, prophylaxis replaces episodic therapy, which has been a frequently used hemophilia treatment regimen since the 1970s.

“Modern hemophilia treatment has completely changed the phenotype—but not in countries where early treatment is not available,” she said.

van den Berg cited a very large U.S. study of patients with severe hemophilia A, divided into four birth-date cohorts. Even in the age group born in the 1980s, disability levels were high, she explained, with on average more than five joint bleeds over six months, despite a very high clotting factor consumption.

The large, international Musculoskeletal Function in Hemophilia (MUSFIH) study of children with severe hemophilia A showed that substantial bleeding occurred even with very high factor dosing, van den Berg said. The study also showed that the number of bleeds—but not the dose of episodic treatment—correlates with joint outcome. Understanding this is key, especially since joint function deteriorates after age 12. And signs of loss of joint function are often visible at puberty due to growth spurts.

van den Berg cited a small, randomized study showing that low-dose prophylaxis, rather than episodic treatment, reduces bleeding by 80 percent. Research also shows that early diagnosis is crucial. “Remember, more than 50 percent of those with severe hemophilia A have a negative family history,” she explained.

But when and how do you start prophylaxis? van den Berg said research suggests that the key is to start earlier than age 3 because physical examination scores, which document joint damage, increase when treatment is delayed. Research also shows that low-dose



WFH Vice-President Medical Marijke van den Berg discusses new breakthroughs in hemophilia treatment

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prophylaxis should be administered at least once a week.

There is a correlation between joint scores and dosage of factor replacement. “With a 1,000-1,500 dose, there’s a lot to gain,” stated van den Berg. The good news for people in developing countries, where factor supply is limited, is that data show that lifetime prophylaxis with 1,000 IU/kg is much more effective than episodic treatment. “You can significantly improve outcome with limited factor consumption,” she stated.

However, to implement low-dose prophylaxis, comprehensive care centres are crucial, van den Berg said. She recently toured two international hemophilia training centers that are excellent examples of this: the centre in Campinas, Brazil, led by Margareth Castro Ozelo, MD, and the centre in Johannesburg,

South Africa, led by Johnny Mahlangu, MD. The Johannesburg centre serves 1,200 patients, with an impressive 35 percent on prophylaxis and home therapy.

Unfortunately, these centres are the exception. Recent data from Africa show that not even 5 percent of people with hemophilia have been diagnosed. “The main reason is because limited or no treatment is available,” van den Berg said.

The WFH Humanitarian Aid Program will substantially address that deficit. From 2016 to 2020, the program plans to provide a predictable supply of 500 million IUs of factor, van den Berg explained. Availability of products will lead to more diagnosis, and that will lead to more training and, in some cases, corrective surgery.

In conclusion, van den Berg said that the evidence shows that only primary prophylaxis can prevent joint disease, and episodic treatment is not an appropriate regimen for severe hemophilia A. When joint bleeds have occurred, signs of arthropathy appear even if very high-dose prophylaxis is given afterwards.



Rodney Camire

## A new and exciting aspect of the coagulation system

All the players in the coagulation system are known—or are they? Thrombin is a key enzyme in the system that controls clot formation; too much or too little can lead to either thrombosis or hemorrhage.

At the medical plenary “Rethinking Events in the Hemostatic Process: Role of Factor V and TFPI,” held during the WFH 2016 World Congress, Rodney Camire of the Children’s Hospital of Philadelphia, U.S.A., explained that a number of inhibitors acting on factor Xa generated through the intrinsic and extrinsic clotting pathways, and on prothrombinase itself, all impact the regulation of thrombin. “By dampening inhibitors you can control thrombin,” he said.

Sharing his expertise with hundreds of attendees, Camire explained, “FV is very similar to FVIII in some ways and needs to be processed at specific sites.” FV however, he elaborated, is a procofactor requiring proteolytic activation including the removal of the B domain. He pointed out that an important step in thrombin generation is the activation of FV to FVa. One role of this B domain is widely believed to be to block FV procofactor activity.

Camire and his research team investigated how two regions of the B domain, the basic region (BR) and the acidic region (AR2), contribute to keeping the molecule in this inactive state. However, they found that there is a discrete segment of the B domain that serves an essential autoinhibitory function, maintaining FV as a procofactor. “Dispensing with this region is the driving force to unveil a high affinity binding site for FXa,” he explained. Camire said that certain Australian snakes have a unique form of FV in their venom that lacks these inhibitory sequences, thereby creating an active procoagulant cofactor.

Tissue factor pathway inhibitor (TFPI) normally exists in two variant forms in the blood: TFPI $\alpha$  and TFPI $\beta$ . TFPI binds FV in plasma, but shows no affinity for FVa. “There are two to three different forms of FV that are generated during the initiation of coagulation that are sensitive to TFPI $\alpha$ ,” said Camire.

Camire also said that new physiologic forms of FV have been reported. Citing research from East Texas (U.S.A.), he described a family of individuals with a moderately severe bleeding disorder that have a mutation in exon 13 of FV, which impacts the splicing of its transcript. The resulting form of FV essentially lacks the majority of the B domain, including the BR, but harbors the acidic region. Known as FV-short, this form of FV has been shown to bind to TFPI $\alpha$ . These patients were shown to have 10 times the normal physiologic level of TFPI $\alpha$ . This, and other research, has given rise to the hypothesis that TFPI $\alpha$  alters the function of different forms of FV(a), which in turn impacts thrombin generation. This is currently a therapeutic target for hemophilia treatment.

Camire concluded that evidence suggests that blocking TFPI function and inhibition of FV activation may enhance coagulation. “Antibodies targeting TFPI are in clinical trials. Specific [FV] B domain sequences are key autoinhibitory elements responsible for keeping FV as a procofactor. Dismantling these sequences drives FV activation.”

# New inhibitor therapies have the potential to change hemophilia treatment

Considering that the treatment of hemophilia with inhibitors remains problematic, and that inhibitors may be an important consideration for new approaches such as gene therapy, it’s particularly relevant that a session during the Congress examined alternative therapies in the management of inhibitors.



Midori Shima

Midori Shima, Nara Medical University, Japan, chaired this session, which was designed to help attendees understand the next generation of treatments for people with hemophilia and inhibitors. “The session aims at summarizing the current concepts of inhibitor development and eradication from the immunological aspect, and presenting emerging novel therapies,” Shima said. David Lillicrap, Queen’s University, Canada, presented new hypotheses of causes of inhibitor and their elimination. Rebecca Kruse-Jarres, University of Washington, U.S.A., discussed how recombinant porcine FVIII constitutes a potent hemostatic therapeutic.

Shima summarized details of clinical trials of three novel therapeutics: an anti-FIXa/X bispecific antibody (emicizumab)—in which he is directly involved—an anti-antithrombin siRNA (fitusiran) and an anti-TFPI antibody (concizumab).

# Gene therapy delivery options explored

This year's WFH World Congress featured a session where scientists involved in gene therapy approaches to hemophilia provided updates on developments in the delivery of therapies via stem cells, genome editing and liver-directed AAV vectors. David Lillicrap from Queen's University, Canada, was the chair of this session and summarized the momentum of clinical gene therapy as remarkable.



Christopher Doering discusses stem cell possibilities.

Christopher B. Doering, Emory University, U.S.A., took the audience through the process of using stem cells in gene therapy for hemophilia A. Stem cell technology was first applied to T cells in the 1990s, but safety concerns necessitated a return of the research back to academic laboratories, said Doering.

“Stem cells are rare populations of unspecialized cells that are self-renewing and can become other cells,” began Doering. “Donor cells from a non-affected individual (from the blood) are transplanted into the patient. In order to apply [this approach] to hemophilia, this may require gene transfer.” Doering added that it is sometimes possible to use the patient’s own cells, harvested peripherally or from bone marrow. In order to implant stem cells, some of the patient’s cells must first be destroyed in order to make “space” for the new cells.

Challenges to combining gene transfer and stem cell technologies in hemophilia include the optimization of transgene expression and product biosynthesis, safe and effective pre-transplantation conditioning, and clinical vector manufacturing, said Doering. “Stem cells can last for the lifetime of an individual so we have a potential cure. We need only to target a few cells as each stem cell will produce hundreds of daughter cells.”

A pilot clinical trial design has been approved by the US Food and Drug Administration, starting with a single site trial at Emory University, U.S.A.

Matthew Porteus, Lucille Packard Children’s Hospital, U.S.A., explained that genome editing is a method to correct disease causing variants. “This is a precise, controlled mutagenesis of the genome. Creating a break in the DNA will cause the cells to look for this and make a repair. So we can stimulate mutations at the site of the break.”

The repair could change the DNA sequence to one that already exists in the genome or to something novel using synthetic biology. This second option “creates a new therapeutic phenotype in the cell. In hemophilia it might be used to overexpress a clotting factor,” said Porteus.

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Homologous recombination to change single nucleotide variants involves delivering an adeno-associated virus (AAV) nanoparticle. “In research with sickle cell disease there is about a 20 percent success rate. We can also insert a gene cassette into a safe harbor or single location in the genome,” said Porteus.

“Targeting transgene addition without knocking out the target gene or knocking a gene into being highly expressed has some exciting applications,” noted Porteus. “There are opportunities and challenges for in vivo gene editing for hemophilia. There would be no need to give patients conditioning agents and it is a potential method to edit cells that naturally make clotting factors.” One drawback however, is a relative inability to monitor efficacy and off-target effects, he added.

Porteus noted that an ethical concern of genome editing is equity and distribution and how to make it available to people with hemophilia in all parts of the world.

Brigit E Riley, Sangamo BioSciences, U.S.A., delivered new data on FVIII gene therapy via AAV delivery. “Using AAV in clinical and

preclinical trials for FIX has been successful, however there is a lag in the clinic for FVIII.”

She said liver-directed AAV FVIII cDNA gene therapy is being explored. Recombinant AAV is efficient and stable long-term in tissues that do not divide such as the liver, brain, and muscle. This provides the potential for long-term production of a gene of interest in the liver. FVIII, however, is not an ideal gene for delivery via AAV as it is constrained by its large gene size and a low efficiency of transcription/translation. These challenges can be partially overcome by multifactorial modifications. “With the modifications, virus yield was improved 8 to 10 fold,” said Riley.

She noted that data from in vitro experiments show good correlation between FVIII activity and levels over a range of doses. In vivo, expression of the hFVIII (human FVIII) cassette from the AAV vehicle in wild-type mice resulted in FVIII expression at twice the normal physiological level. Further experiments in a hemophilia A mouse model demonstrated in vivo FVIII activity three times normal physiological levels with levels remaining stable over time. A reduced bleeding time was also observed. In non-human primates, similar in vivo experiments resulted in FVIII at four to six times normal physiological levels. “Follow-up dose finding studies are aimed at determining minimal dose,” said Riley.

Despite all of these exciting advances, the challenge of financial incentives remains to be addressed. Porteus pondered, “With no established reimbursement model for a one-time gene therapy, it begs the question, ‘Are stakeholders willing to take a chance on experimental curative therapies that have a different conceptual basis, when the current paradigm has transformed the lives of hemophilia patients?’”



# The Face of Inhibitors:

## Patients, families, and caregivers share their stories

Inhibitors affect between 20 and 40 percent of people with severe hemophilia A. During the WFH 2016 World Congress, patients, families, and caregivers impacted by this rare condition participated in a panel discussion that put a face on their trials and triumphs.

Kari Atkinson, with her 13-year-old son Beau by her side, gave a moving presentation on what life has been like for her, Beau, her husband Craig, and their daughter Jordan since Beau was diagnosed with hemophilia and an inhibitor.

When Beau was only 6 months old, he was diagnosed with severe hemophilia A. Kari and Craig were shocked because there was no known history of hemophilia in their family. However, they had no idea things were about to get worse.

When Beau had a routine blood test at 18 months old, the doctors discovered an inhibitor. “That inhibitor detection literally rocked our world,” Kari said. “It is so different from normal hemophilia. We prayed every night that we could just have normal hemophilia.”

Beau’s inhibitor affects the whole family, Kari explained. “For anyone in this room, you know the number of tears and sleepless nights.” The inhibitor initially had a low titer, and the first treatment proved effective for four years. When it was no longer effective, the next treatment could only be used for a year. Since 2012, Beau, his family, and his caregivers have been struggling with managing his inhibitor trying different factor treatments and twice inserting ports.

“The cost of care went from \$250,000 annually with hemophilia to \$1 million to \$1.5 million per year with the inhibitor, depending on the number of bleeds,” Kari said.

Managing Beau’s hemophilia and inhibitor is a true family commitment, Kari stated. “We have to be on high alert at all times. [When a bleed occurs], minutes is our reality between walking, crutches and a wheelchair. It doesn’t matter if we’re in the car, at the amusement park—we infuse.”

At school, Beau stands at the back of the line so he won’t be jostled. He can’t participate in recess activities. But his friends are very supportive. “Other inhibitor patients are like a family beyond a family beyond a family,” Kari said.

“It takes a village to raise a child with hemophilia and an even larger village to raise a child with an inhibitor.”

But there are plenty of positives, Kari said, as Beau smiled beside her. Beau currently receives



Beau Atkinson watches as his mother Kari discusses how the family copes with his severe hemophilia A, compounded by an inhibitor.

immune tolerance induction treatment every other day with an extended half-life factor. His inhibitor levels initially spiked, but now they are steady.

Augustus Nedzinkas, a 29-year-old Lithuanian, was diagnosed with hemophilia A with an inhibitor when he was 14 months old. Hemophilia treatment was rudimentary in Lithuania at the time, and, “Sometimes the bleeding wouldn’t stop until the joint had expanded to the max,” he said.

Nevertheless, he was still able to attend public school, graduate from university, get a full-time job, and even scuba dive.

Augustus had low inhibitor levels for several years, so in 2012, his doctors decided to try a high-dose immune tolerance treatment of 100 IU/kg twice daily. This type of treatment had never been used before in Lithuania, but it was a success. Augustus’ inhibitor dropped below zero in the first month.

“Then they prescribed daily prophylaxis and that made my life very happy,” he said. “The first thing I did was go spear fishing and get my trophy fish. I changed my car’s gear box from an automatic to a manual. And I got married.” He has a knee replacement scheduled for next year. “Now I can plan things and expect my health won’t be an issue—all I have to do is infuse myself every morning,” he said.

Kuixing Li, a nurse at Peking Union Medical College Hospital in China, talked about inhibitors from a caregiver’s standpoint.

One of her patients was a 9-year-old boy with an inhibitor. “He was in a wheelchair, and he

often lost his temper and was always angry,” Kuixing said. “Sometimes he wanted to give up his treatment.” His family couldn’t afford factor and had to use prothrombin complex concentrates (PCC) instead.

The boy eventually left the hospital after suffering a brain bleed. One day, Kuixing called his grandmother to see how he was doing. “This is not a good story,” she said, her voice breaking. “I found out he died—they could not stop his bleeding.”

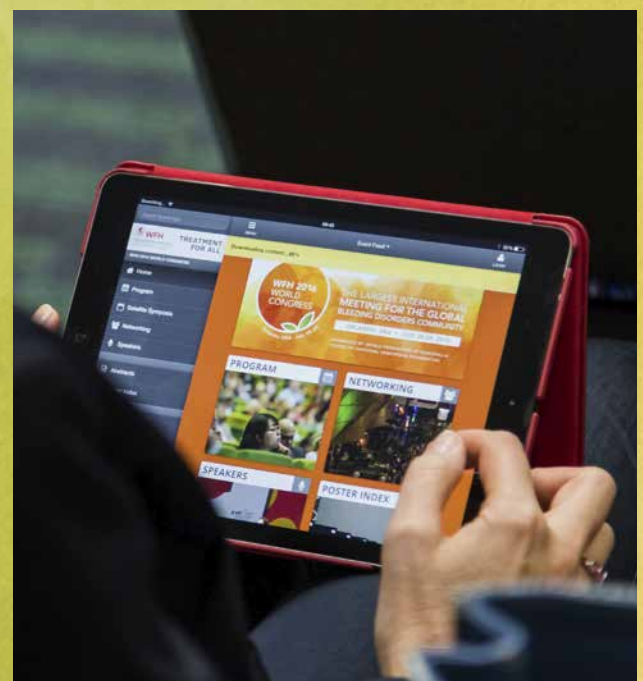
This is not an unusual occurrence in China, which is home to an estimated 100,000 to 150,000 people with hemophilia. “Sometimes I think if the WFH wants to establish their goal of Treatment for All, they should move their office to China,” Kuixing said with a laugh.

In 2015, there were only 31 hemophilia treatment centres throughout China—but that’s a notable increase from the six centres in 2007. There are also only about 20,000 patients in the national registry.

After a national program from 2008 to 2011 to screen people with hemophilia for inhibitors, Kuixing said the Chinese developed an inhibitor management plan that includes PCC infusion after bleeding and low-dose prophylaxis. It works for about 50 percent of patients, she said. Meanwhile, Chinese chat rooms are full of inhibitor patients who can’t afford factor treatment, so they opt for dangerously high doses of PCC.

“It’s a big challenge for caregivers to give good care for hemophilia patients in China,” Kuixing said.

# The WFH 2016 World Co



# Congress in pictures



# Think of self-care in a new way

In 2007, Patrick Lynch's younger brother, Adam, died of an intracranial bleed at age 18. Both Patrick and Adam were born with severe hemophilia A.

Patrick was only 22 at the time. "As you can imagine, the months and, quite frankly, the years that followed were challenging. I remember saying, '[Hemophilia] got him. It's not supposed to happen to us anymore, but it got him,'" Patrick said during the "Empowerment Through Self-Care" plenary at the WFH World Congress this July.

Desperate to discover why Adam died, Patrick searched for a clue. He found it in the bottom of a duffel bag buried in a corner in Adam's college dorm room. The bag was full of factor. Patrick suspects his brother had stopped his prophylaxis.

"I spent a considerable amount of time thinking about why he fell off his regimen," Patrick said. "I finally determined that it was because my brother never identified as having a bleeding disorder. That took him off his regimen."

Patrick has never felt the same way. He developed an inhibitor as a child, but immune tolerance induction eradicated it when he was 13. He was able to go on prophylaxis and live, as he refers to it, "A much more empowered life." He got involved in high school theater and majored in acting at Boston University.

Patrick has always valued self-care for his hemophilia, but Adam's death made him realize that others—particularly children—may not.

"It made me think about how we as a community are engaging young people," he said. "And I saw an opportunity to use my



Patrick Lynch speaks at Wednesday's Self-Care plenary.

acting background to create something that didn't exist." His brother didn't connect to the bleeding disorders community in traditional ways, but like many young people, he loved comedy and the internet.

So Patrick formed a company, Believe Unlimited, and created an online comedy series styled after the TV show "The Office." Dubbed "Stop the Bleeding," the series—available at [stbhemmo.com](http://stbhemmo.com)—is a mockumentary about a dysfunctional bleeding disorders nonprofit organization. It uses humor to tackle serious topics like self-care and self-infusion, women with bleeding disorders, and the history of hemophilia.

"We want to teach young people with a bleeding disorder, but we really want to inspire them," Patrick said. The goal is to replace the stigma and fear of hemophilia with the idea that the disease can be "Funny or cool or even uplifting," he said.

Since launching "Stop the Bleeding," Patrick's company has also created a live speaker series called "Powering Through"; the Impact Awards to recognize teens with bleeding disorders; a monthly podcast called "Bloodstream"; and a claymation series called "Helping Hany" that examines the psychosocial implications of being a girl with a bleeding disorder. He has also produced videos for the WFH Treatment for All series.

All of this fits within Patrick's definition of self-care. "My journey and understanding of self-care has evolved," he said. "It's not just self-infusing, stretching, and maintaining a good diet. For me, self-care is giving back to and empowering the community."

He also acknowledges that he has a "Privileged definition of self-care—a privilege not shared by 75 percent of our community in developing nations." That's why he believes people from the developed world have an obligation to help others who aren't able to self-infuse or do other aspects of self-care because they lack treatment options. This can include asking product manufacturers how they help people in developing countries and contributing to the WFH Humanitarian Aid Program.

"I miss my brother. For years, I thought about him every day," Patrick said, his voice breaking. "Let's continue to ramp up our efforts for our brothers and sisters in developing countries so one day they too may enjoy a privileged definition of self-care."

## WFH signs memorandum of understanding with the Asia Pacific Hemophilia Working Group to support healthcare professionals in the region

The World Federation of Hemophilia (WFH) will collaborate with the Asia Pacific Hemophilia Working Group (APHWG) to help improve care for people with hemophilia and other hereditary bleeding disorders in the Asia Pacific region. The APHWG consists of clinicians managing hemophilia from countries

across the regions and is led by Alok Srivastava, MD.

The pilot phase for this collaboration will begin this fall, with both parties sharing work plans for 2016 and 2017. This will ensure that development work done in the Asia Pacific region will be complementary and will support

existing WFH program activities. The primary focus of the APHWG will be on education, training, and research.

The WFH will continue its outreach efforts in the Asia Pacific region and believes this partnership will benefit those most in need, furthering our vision of ensuring Treatment for All.

# Lessons from NASA: What is an appropriate level of risk?

Since the 1980s, when about 10,000 people with hemophilia tested positive for HIV after receiving contaminated blood, assessing and managing risk has been a core principle in the bleeding disorders community. This applies not only to blood supplies that can be infected with both known and unknown viruses, but also to the development of new treatment products.

In the Wednesday morning plenary “Managing the Risk of Human Space Flight: Lessons From 50 Years of NASA Human Space Flight,” Michael Lutomski, a former international space station risk manager for NASA, noted that both the hemophilia community and NASA operate in environments that do not tolerate risk or failure. And yet, risk is unavoidable. So what is the best way to deal with these types of situations?

One key is continuous risk management, Lutomski said. We already do this almost every day of our lives, he said, using the example of choosing a flight to Orlando to attend this congress. For instance, you may have managed the risk of missing a connecting plane by choosing a longer connection time.

NASA has a mind-boggling level of risk, Lutomski said, with a 3.4 percent failure rate in launches each year. “Can you imagine crossing the street or driving a car with those odds—you’d never do it,” he said.

And yet, Lutomski said the common perception—even at NASA—was that space flight had the same level of risk as flying on an airplane. However, in 1986, the Challenger explosion changed that—much like the AIDS crisis changed the common perception that blood transfusions were inherently safe.

NASA responded to the Challenger crisis by rethinking how it handled risk. It instituted a risk-based decision-making framework and a risk threshold. Astronauts sign statements noting that they understand risks like a death rate of one out of every 270 crew members on a six-month expedition to the International Space Station. “We now have a more healthy

realization of what risks we’re really taking,” Lutomski said.

One of the best ways to mitigate risk is to self-report, Lutomski said. But people have many reasons for not participating in risk assessment and reporting. They think they have no risk, their programs are too small, making risk public will kill a program, they prefer to deal with problems as they arise, identifying risks is bad for their career, it’s not their job to fill

out bureaucratic forms, or they can’t assess risk because they can’t predict the future.

Not only does a successful risk-management system need to overcome those arguments, but it also needs to be humble and open to new information, Lutomski said. At NASA, that translates into continually questioning performance, looking at risks, and responding appropriately to failures when they occur.



Michael Lutomski compares the risks involved in the practice of medicine and space flight operations.

## Donors of Congress: Ekawat Suwantaraj

One of the best memories at the WFH 2016 World Congress Resource Centre came in the form of Ekawat Suwantaraj, a talented, smiling member of the bleeding disorders community from Bangkok, Thailand. Ekawat lives with severe hemophilia A, but he never lets it stop him from bringing smiles to people’s faces with his talent. He began drawing caricatures two decades ago and first shared his talents with the WFH community at the WFH Hemophilia 2004 World Congress, returning this year to draw in exchange for a donation to the WFH Humanitarian Aid Program. He raised \$600 through his efforts in a just a few hours and delighted many delegates with a new version of their best self.



Ekawat Suwantaraj

Our community gives back in many ways, some devote time through volunteering, some give of their talents while others provide financial support. We are thrilled that Ekawat gave his time and talent to help us raise money for the WFH Humanitarian Aid Program.

# WFH Humanitarian Aid Program: Lasting change for those most in need

The success of the WFH Humanitarian Aid Program firmly rests on ensuring a sustainable and predictable supply of treatment products. Evidence of this success was illustrated during the session “Humanitarian Aid: Treatment for all is the vision of all” on Tuesday morning.

Assad Haffar, WFH Humanitarian Aid Director, chaired and opened the session highlighting the reality for many around the world living with a bleeding disorder. In numerous developing countries, the lack of access to treatment is an urgent need and an important public health challenge. Since 1996, 322 million IUs have been donated to 90 countries, directly helping over 100,000 people who are in urgent need. The expansion of the WFH Humanitarian Aid Program will now include over 500 million donated IUs in a five year period, providing a predictable supply and permitting planning and forecasting for the first time for the WFH.

Megan Adediran, Executive Director of the Haemophilia Foundation of Nigeria (HFN), began her talk explaining how her organization was created. It was the first treatment donation from the WFH that spurred her to create HFN. As diagnosis rates within Nigeria have increased, so has the need for access to treatment products. The expansion of the WFH Humanitarian Program has also impacted the bleeding disorders community significantly beyond providing lifesaving treatment. Before the expansion began in 2015, only 178 patients were diagnosed in Nigeria. One year later that number increased to 271 patients as word has spread that predictable treatment is now available. “The WFH Humanitarian Aid Program has given hope to families,” said Adediran. “That’s what this program has been able to do for the people of Nigeria.”

Each speaker during this session outlined how improving and sustaining care for those most in need is imperative. Thomas Sannié, President, the Association française des hémophiles (AFH), spoke about how the AFH is working together with the WFH to improve the situation in French speaking countries in sub-Saharan Africa through the Franco-African Alliance for the Treatment of Hemophilia (AFATH). “What motivates us to act is a vision shared with all our partners to bring treatment to all sufferers of bleeding disorders,” said Sannié.



.....  
Before the expansion began in 2015, only 178 patients were diagnosed in Nigeria. One year later that number increased to 271 patients as word has spread that predictable treatment is now available.  
.....

Kibet Shikuku, MD, Chairman of the Kenya Haemophilia Association, further illustrated the need for the WFH Humanitarian Aid Program. He emphasized that education and research needs to go along with these donations.

As Ahmed Naseer was unable to speak at this session, his hematologist Shasahi Apte, MD, described Naseer’s journey to receive knee replacement surgery. It was only through donations from the WFH that his surgery was made possible, further demonstrating the impact of support for those most in need.

The session concluded with a final thought from Haffar, “Together, we can make the impossible possible.” To learn more about the WFH Humanitarian Aid Program, visit [www.treatmentforall.org](http://www.treatmentforall.org).



Dr. Eun Chul Huh, Green Cross President, and Alain Weill, WFH President

## WFH Announces multi-year humanitarian aid agreement with Green Cross

The World Federation of Hemophilia and the Green Cross Corporation signed a three-year agreement on Monday July 25, 2016, to contribute a total of six million international units (IU) of its recombinant FVIII product to the WFH Humanitarian Aid Program.

Dr. Eun Chul Huh, Green Cross President, and Alain Weill, WFH President, signed this agreement during the WFH 2016 World Congress in Orlando, Florida. With multi-year donations—such as this commitment from Green Cross—and a steady flow of treatment products to the WFH network, it will become increasingly possible for people with bleeding disorders in the developing world to access treatment for emergency situations, acute bleeds, corrective surgeries, and also prophylaxis for young children.

“We are honoured by this commitment by Green Cross to the WFH Humanitarian Aid Program,” said Weill. “This donation will help to improve the lack of access to treatment products in developing countries by providing consistent and predictable access to Treatment for All.”

# WFH Global NMO Training: Supporting bleeding disorders communities all over the world.



The WFH leads many endeavours that aim to support bleeding disorders communities all over the world. One of our key programs for doing that is the WFH national member organization (NMO) trainings and capacity-building workshops. These events are held at national and regional levels to strengthen the knowledge and skills of NMOs and help them improve their internal structures as well as their external activities and relations. The workshops are designed around the needs of NMOs and address a range of important topics: fundraising, conflict resolution, women with bleeding disorders, advocacy and lobbying, pharmaceutical relations, and event planning.

Before every WFH World Congress, the WFH holds a three-day Global NMO Training. This year, the training was held from July 21 to 23 at the Gaylord Palms Resort and Convention

Center in Orlando, U.S.A. The program covered many topics of interest to NMOs, including strategic planning, implementation of projects, developing care for hemophilia, and volunteer development. It will also feature collaborative social activities and joint sessions with the National Hemophilia Foundation (NHF). The 2016 event was a very special one, because it marked the first time the WFH hosted a Global NMO training in parallel with the NHF Annual Meeting.

All Global NMO Trainings include the participation of one patient representative chosen from each WFH NMO. The selected person participates with their peers from around the world in topical plenaries and workshop trainings. This year's event also included the WFH Youth Fellowship Program. Of the 50 submissions we received from NMOs, 21 youths were selected. In addition to

participating in the Global NMO Training, the selected Youth Fellowship Program candidates received free airfare to Orlando, free Congress registration and accommodation, and they also were able to attend the WFH Annual Meeting of the General Assembly as observers.

In addition to the training aspect of NMO events, there is also an important networking aspect that cannot be overlooked. The training sessions tend to be with smaller groups, which means that attendees had a chance to “break the ice” before the WFH 2016 World Congress started. Many attendees have said that the NMO training event is an excellent way for them to make new friends, meet new contacts and prepare for the Congress.

To find out more about the WFH Global National Member Organization Training, visit the WFH NMO Skills training page.

## Celebrating the WFH Twinning Program at Congress

The WFH Twinning Program Event held on July 27 during the WFH 2016 World Congress was a special opportunity for participants to connect, share, and inspire others to join a movement that partners hemophilia treatment centres (HTCs) and patient organizations in developed and developing countries.



The program's objective is to improve hemophilia care in emerging countries through a formal, four-year, two-way partnership.

The event featured presentations by the two respective 2015 Twins of the Year Award winners. Marion Stolte and Eric Stolte from the Canadian Hemophilia Society shared their “journey together” with the Bangladesh Hemophilia society. In addition Hans Hermann-Brackmann, MD, from the University Hospital Bonn (Germany) shared

the “story in pictures” of their partnership with the St. Marina University Hospital (Varna, Bulgaria).

With a panel discussion led by WFH Hemophilia Organization Twinning Committee Chair Sharon Caris, and remarks from WFH President Alain Weill, the event was also an opportunity to highlight the 15th anniversary of the sponsorship of the program by Pfizer. Michael Goettler, the Pfizer Global President, Rare Diseases for the Global

Innovative Pharma Business expressed pride in supporting a program that continues to have a profound impact on the global bleeding disorders community.

Many peer-to-peer connections were made at the event and throughout Congress, and the WFH is looking forward to supporting the development of new twins in the years to come.

*The Twinning Program is supported by exclusive funding from Pfizer.*

# Awards Ceremony recognizes those who have made a difference

The WFH Awards Ceremony, held during the WFH 2016 World Congress, recognizes those individuals who have inspired all of us by generously giving their time, expertise and passion to the inherited bleeding disorders community and the WFH.



## AWARD

### Inga Marie Nilsson Award

Given to an individual or pair of WFH volunteers for their contribution to developing hemophilia care based on their own initiative and for contributing new ideas and projects

### Henri Chaigneau Award

Rewards scientific research that improves knowledge about the pathology, the treatment or the prevention of bleeding disorders

### Hemophilia Organization Twins of the Year

Recognizes Twins that have helped improve hemophilia care by strengthening and developing hemophilia organizations through the transfer of skills, resources, and information

### Hemophilia Treatment Centre Twins of The Year

Recognizes Twins that have helped improve hemophilia care by strengthening and developing hemophilia treatment centres through the transfer of skills, resources, and information

## RECIPIENT

### Frederica Cassis

### Professor Thierry Vandendroessche Professor Marinee Chuah

2014 - **The Asociacion Nicaragüense de Hemofilia and the Quebec Chapter of the Canadian Hemophilia Society**, represented by Denis Antonio Martinez Artola and Antonio Rivas Javier Ojeda from The Asociacion Nicaragüense de Hemofilia, and Patricia Stewart and Francois Laroche from the Quebec Chapter of the Canadian Hemophilia Society.

2015 - **The Hemophilia Society of Bangladesh (HSB) and Canadian Hemophilia Society (CHS)**, represented by Dr. Mohiuddin Khan on behalf of The Hemophilia Society of Bangladesh, and Marion Stolte from the Canadian Hemophilia Society

2014 - **Arequipa (Peru) and Los Angeles (USA)**, represented by Dr. Willy Quinones from the Hospital Nacional Carlos Alberto Seguin Escobeldo, and Dr. Guy Young from the Children's Hospital Los Angeles

2015 - **Varna (Bulgaria) and Bonn (Germany)**, represented by Professor Valeria Kaleva from the St. Marina University Hospital of Varna, and Dr. Anni Pavlova, Professor Johannes Oldenburg, Dr. Christine Brackmann and Dr. Hans-Hermann Brackmann from the University Hospital Bonn





# WFH 2016 AWARDS CEREMONY

Join us to celebrate the WFH's most prestigious awards

ORANGE COUNTY CONVENTION CENTRE  
July 28, 2016  
8:00am - 12:15pm to 12:30pm



## AWARD

### Henri Horoszowski Award

Encourages musculoskeletal specialists to become involved in hemophilia care

### Susan Skinner Memorial Fund Scholarships

Established as an endowment to support the training and education of young women with bleeding disorders

### WFH Clinical Research Grant

Provides support for international clinical investigation relating to inherited bleeding disorders

### Young Researcher Award

Awarded to researchers who have submitted highly rated abstracts in any discipline involving hemophilia and other related bleeding disorders

### International Healthcare Volunteer Award

Honours a volunteer healthcare professional who has contributed significantly to further the mission and goals of the WFH

### International Frank Schnabel Volunteer Award

Honours an individual with hemophilia, or a family member of a person with hemophilia who has contributed significantly to further the mission and goals of the WFH

## RECIPIENT

### Fabio Souza

2015 - **Michelle Cecil** and **Joelle Palmatier**

2016 - **Ashley Taylor-Fowlie** and **Claudia Teresa Peña Villena**

2015 - **Victor Jiménez-Yuste, Marzia Menegatti, Silvia Riva** and **Jonathan C. Roberts**

2016 - **Arijit Biswas, Hervé Chambost** and **Yves Guillaume**

### Mahasen Saleh

### Christopher Mwaniki

### Jamie O'Hara

### Shannon Jackson

### Lakshmi Srivaths

### Aarti Shah

### Lisette M. Schütte

### Kristina Kihlberg

### Fabio Souza

### Pu-Lin Luo

### Lily Heijnen

### Mark Skinner





L to R – Mark Skinner (WFH USA President), Maria Manahan (Hemophilia of Georgia President), Alain Weill (WFH President), Val Bias (CEO National Hemophilia Foundation), Alain Baumann (CEO WFH) and Jorge Della Riva (Chairman NHF)

## Proudly supporting the global community

Humbled and inspired by the spirit of generosity pervading the WFH 2016 World Congress and National Hemophilia Foundation (NHF) Annual Meeting, the WFH Philanthropy Resource Team wants to say thank you loudly to the hundreds of patients, healthcare professionals and volunteers who stopped by the WFH Resource Centre during Congress. We are grateful to have met so many new friends!

Thank you to the 368 donors—from 92 countries—who supported the WFH Humanitarian Aid Program and made their mark on the WFH World Map. Your generosity spanned the globe from Nigeria to Costa Rica and your contributions represent a vote of confidence in the work we do every day in pursuit of our shared vision of Treatment for All. And to the over 750 of attendees who renewed or purchased their first WFH Membership we are delighted to be in touch with you in the coming months.

Thank you to the 28 NHF Chapters that answered the call to become Champions for the WFH Humanitarian Aid Program and raised \$139,800 in support of WFH USA. In particular, we would like to thank our two founding Champions:

National Hemophilia Foundation and Hemophilia of Georgia, Inc., as without the support of their leaders Val Bias and Maria Monahan, the results to date would never have reached this level of success.

Most of all, thank you to the patients and leaders from the global bleeding disorder community. Your perseverance and optimism in the face of enormous challenges are the well from which we draw the energy to continue our work on your behalf. We are proud to work alongside you in making a global impact on the lives of those living with a bleeding disorder regardless of where they live.

Please join the Donors of Congress today by making a gift online at [www.wfh.org/donate](http://www.wfh.org/donate).

## IHTC-RtW Joint Event at Congress: Discussing real-world solutions

During the WFH 2016 World Congress, a very unique meeting took place, designed to showcase and discuss real-world solutions: the International Hemophilia Training Centre-Reach the World (IHTC-RtW) Fellowship Programs Joint Event. Participants were from the International Society on Thrombosis and Haemostasis (ISTH) and the World Federation of Hemophilia (WFH).

The event took the form of a moderated panel and roundtable discussions, and allowed participants—both trainers and alumni of the IHTC and RtW programs—be face-to-face with their peers from around the world, and have productive conversations on the topic of how to raise awareness of the value of empowering healthcare professionals through education and training. The moderator of the event was Mike Makris, MD, the outgoing Chair of the IHTC Committee. Panel members included Philippe de Moerloose, MD, and Evelien Mauser-Bunschoten, MD, (trainers) as well as Zhenping Chen, MD, and Cesar Haddad (alumni). The goal was to bring together two influential leadership and capacity building programs, as well as to highlight the success of the alumni in improving care for bleeding disorder patients in their countries.

Participants from over 20 countries took part in the discussions, all of whom had been involved in some form of IHTC and RtW Fellowship Training Programs. Groups sat at tables that were limited to ten people in order to keep the conversations familial and ensure that everyone had a chance to speak and share their views. Several questions were asked by moderators in order to spark positive discussions, such as, “What was the highlight of your fellowship training?”, “What would be useful for future individuals to learn during a fellowship?” and “What would you do different or what are the things that should be improved for future trainees?”

The event concluded with a networking session. Many attendees said that they left feeling like they had made a significant difference in the world of hemophilia, thrombosis, and hemostasis through their participation in the IHTC and RtW Programs. There was also a sense that more improvement and development was just around the corner for them and for future program participants.

*The WFH would like to thank Bayer for their exclusive support of the IHTC program.*



# The WFH eLearning Platform launches: one stop for easy access to all bleeding disorder resources

The WFH is proud to announce the launch of a major advance in its educational resources for the bleeding disorders community at the 2016 World Congress: the WFH eLearning Platform. Designed to support education worldwide, the portal puts content and tools at the fingertips of anyone with a computer or mobile device and an internet connection.

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The WFH eLearning Platform brings together introductory information and more in-depth resources in eight themed eLearning centres: Inherited Bleeding Disorders, Introduction to Hemophilia, Carriers and Women with Hemophilia, Inhibitors, Prophylaxis, von Willebrand Disease, Rare Clotting Factor Deficiencies and Inherited Platelet Disorders. This intuitive grouping greatly facilitates access to the many invaluable resources that the WFH offers the bleeding disorders community.

Filtered search queries of the hundreds of resources in the WFH collection complement the eLearning centres. Searches can be narrowed down by category (article, book, fact sheet, etc.), resource type (webinar, ePoster, video, etc.), author, or language. And of course, Google-like keyword searching is just a few keystrokes away. Users can also make use of a powerful interactive resource navigation

tool that lets them explore content through the six pillars of the WFH Comprehensive Development Model: government support, care delivery, medical expertise (including multidisciplinary), treatment products, patient organizations, and data collection and outcomes research. What's more, the platform lets users know about recently added material, and even gives them a glimpse into what information is most frequently consulted by other users.

“The WFH is committed to supporting the bleeding disorders community internationally,” explains Alain Weill, WFH President. “And one of the best ways to offer that support is by providing easy access to educational resources, whether that’s illustrated explanations for a recently diagnosed child, technical demonstrations that help a laboratory scientist efficiently perform a diagnostic assay, or an interactive module that brings the complex content of the Treatment Guidelines to life for patient advocates and healthcare professionals. The new WFH eLearning Platform does all of this by making our bleeding disorders educational resources easily available to anyone and everyone.”

Available tools cover nearly everything someone involved in the field of bleeding disorders could need, including interactive modules presenting the WFH Guidelines for the Management of Hemophilia, a laboratory manual, an online registry of clotting factor concentrates, a pictorial introduction to hemophilia and a compendium of assessment tools.

Once a user has found educational content to explore, the eLearning Platform offers them powerful functionality to help them access exactly what they’re looking for, quickly and easily. For example, lab manual demonstration videos are complemented by complete searchable transcripts and even the ability to instantly jump to specific sections of the video corresponding to keywords of interest.

The WFH eLearning Platform officially launched at the WFH 2016 World Congress, and delegates could test drive it at the WFH Resource Center. There are already hundreds of educational resources available and new content is constantly being added. Visit [eLearning.wfh.org](http://eLearning.wfh.org) to take a look for yourself right now and learn more about the bleeding disorder topics of interest to you.



# WFH 2016 Annual Meeting of the General Assembly

The 2016 Annual Meeting of the WFH General Assembly was held on July 29, right after the completion of the WFH 2016 World Congress and the meeting covered many topics of interest to WFH members and stakeholders.

The frequency of WFH General Assembly meetings was changed from one every two years to once a year in order to conform to the new Canadian Not-for-Profit Corporation Act. In order to make the process as efficient as possible to everyone involved, the WFH will adopt an innovative virtual WFH Annual meeting in non-Congress years. In-person meetings will continue to be held in Congress years.

Eight new member organizations were welcomed to the WFH, bringing the total to 134. Japan and Suriname became full WFH national member organizations (NMOs). Burkina Faso, El Salvador, Madagascar, Malawi, Myanmar and Namibia were added as associate WFH NMOs.

Alain Weill was re-elected as WFH President and several other candidates were voted to the WFH Board of Directors. Read more about the new additions to the board team in the “WFH Board of Directors: Welcoming new and thanking outgoing members” article in this issue of Hemophilia World.

WFH President, Alain Weill; WFH Vice-President Finance Eric Stolte; WFH Vice-President Medical, Marijke van den Berg, MD; and WFH CEO, Alain Baumann, all delivered highlights from their respective 2016 Annual Meeting reports. The presentations shared a common overall theme: the WFH is making significant progress both in terms of delivering aid to developing countries and expanding its training and support worldwide.

The afternoon session of the 2016 Annual Meeting of the General Assembly saw the announcement of the location for the WFH 2022

World Congress. Jens Bungardt, WFH Congress and Meetings Director, and Alain Weill explained the challenges the WFH faces in the near future. Two major issues were discussed. The first was the fact that the ISTH is moving to an annual meeting in 2020, which means that every second year there would be two major meetings covering inherited bleeding disorders. Weill addressed this challenge and said that the WFH must develop a strategic plan to steer the organization through the changing environment.

The second issue was that none of the potential Congress finalist destinations were able to offer proposals that would ensure the continuation and future development of the WFH. Bungardt compared the projected costs of the proposals received to previous Congresses—including the WFH 2014 World Congress in Melbourne and the WFH 2016 World Congress in Orlando—and clearly showed that the costs of the bidding cities were very high compared to any recent locations used by the WFH in the last decade.

Consequently and in accordance with Article 23.1, “World and Regional Congresses” of the WFH Constitution and By-laws, the WFH Board exercised its right to select the destination that would best serve the needs and objectives of all WFH stakeholders and the WFH community, while giving the WFH the resources necessary to fulfill its mission.

The Board announced that after careful deliberation and analysis, the selected destination for the WFH 2022 World Congress would be Montreal, Canada. Many NMOs made helpful comments both for and against the choice, and in the spirit of Treatment for All, a motion was made to ascertain the support for the Board’s choice of the 2022 Congress venue. The vote ruled in favour of the decision to hold the Congress in Montreal. The Board would like to thank the NMOs—and all those in attendance at the General Assembly—for their feedback, engagement and passion for the mission of the WFH.

## Hemophilia Alliance Supports U.S. Healthcare Professional Continued Training

WFH USA is pleased to announce the first installment of Hemophilia Alliance Travel Grants which will begin this year in time for the WFH 2016 World Congress. This grant will advance the art and science of bleeding disorders nursing, psychosocial work, dentistry, physiotherapy and laboratory sciences. Funded through the generous grant support from the Hemophilia Alliance, a \$15,000 grant per year is committed to support scientific exchange and global learning through attendance of one American member, from selected WFH multidisciplinary committees, at international meetings of the WFH.

# WFH Board of Directors: Welcoming new and thanking outgoing members

On July 29, 2016, the Annual Meeting of the WFH General Assembly was held in Orlando, Florida, and WFH national member organizations cast their votes for the 2016-2018 Board of Directors and the position of WFH president. Each candidate during this election had a unique skill set to offer—but what was most inspiring was that every candidate brought the same commitment to the WFH and the same willingness to volunteer in the name of Treatment for All.

Alain Weill was re-elected for a second term as WFH President. Voting also saw Deon York, Magdy El Ekiaby and Glenn Pierce re-elected. The newest WFH board members are Carlos Safadi of Argentina and Predrag Mikov of Serbia.

The WFH would like to thank all outgoing members of the board for their commitment to our organization and the bleeding disorders community. Their dedication and efforts contributed to many of our organization's

recent achievements, including a very successful WFH 2016 World Congress in Orlando this past July.

To new members, we—and the bleeding disorders community—say welcome and thank you. Our board members and the WFH staff look forward to collaborating with you as we continue to serve the bleeding disorders community—and begin ramping up for our next Congress in Glasgow in 2018.

## WFH BOARD OF DIRECTORS 2016-2018

**Alain Weill**  
President  
France

**Marijke van den Berg, MD**  
Vice President Medical  
Netherlands

**Eric Stolte**  
Vice President Finance  
Canada

**Magdy El Ekiaby, MD**  
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**Jerzy Windyga, MD**  
Medical Member  
Poland

**Cesar Garrido**  
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Venezuela

**Glenn Pierce, MD**  
Medical Member  
U.S.A.

**Flora Peyvandi, MD**  
Medical Member  
Italy

**Predrag Mikov**  
Lay Member  
Serbia

**Carlos Safadi**  
Lay Member  
Argentina

**Deon York**  
Lay Member  
New Zealand

## CO-OPTED

**Saliou Diop, MD**  
Medical Member  
Senegal

**Barry Flynn**  
Lay Member  
U.K.



## WFH 15TH INTERNATIONAL MUSCULOSKELETAL CONGRESS

Seoul, Republic of Korea  
May 5-7, 2017



**WFH**

WORLD FEDERATION OF HEMOPHILIA

WORLD  
HEMOPHILIA  
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APRIL 17  
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New York , New York, USA



The Bell Tower,  
Perth, Australia



Ostankino Tower,  
Moscow, Russia



COSI, Columbus,  
Ohio, USA



Story Bridge,  
Brisbane, Australia



Niagara Falls,  
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World Hemophilia Day is supported by funding from:  
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# Thank You

To the sponsors and supporters who have committed to contributing to the mission of Treatment for All.

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Jan Willem André de la Porte

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### WFH Research Program

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Shire

### WFH eLearning Centres:

Visionary Sponsor  
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### Website localization projects:

Arabic: Pfizer  
Japanese: Biogen  
Russian: SOBI  
Simplified Chinese: Bayer

### WFH Humanitarian Aid Program

Bayer  
Biogen-SOBI  
Biotest  
CSL Behring  
Grifols  
Precision BioLogic  
Shire

### Other sponsored programs

Data Collection and Use of Data in Bleeding Disorders Training Workshop: Shire  
Inga Marie Nilsson Award: Octapharma

Susan Skinner Memorial Fund:

Hemophilia Alliance Foundation  
von Willebrand Disease Workshop: LFB

Youth Leadership Development  
Workshop: F. Hoffmann-La Roche Ltd

### World Hemophilia Day

Bayer, CSL Behring, F. Hoffmann-La Roche Ltd, Novo Nordisk, Precision BioLogic, SOBI

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National Hemophilia Foundation (USA)\*  
Phillips 66  
Pierce Douglas Living Trust  
Rocky Mountain Hemophilia & Bleeding Disorders Association

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

# Calendar of events

## EHC Annual Conference

October 7-9, 2016  
Stavanger, Norway  
Email: [office@ehc.eu](mailto:office@ehc.eu)  
[www.ehc.eu](http://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  
Fax: +7 (495) 960 21 91  
Email: [apoziturina@ctogroup.ru](mailto:apoziturina@ctogroup.ru)  
<http://cith2016.ru/en/>

## IPFA 2nd Asia Workshop on Plasma Quality and Supply

March 2-3, 2017  
Yogyakarta, Indonesia  
Tel.: +31 20 512 3561  
Email: [info@ipfa.nl](mailto:info@ipfa.nl)  
[www.ipfa.nl/events](http://www.ipfa.nl/events)

## Spanish Hematology Meeting

April 20-21, 2017  
Buenos Aires, Argentina  
[www.acamedbai.org.ar/iihema.php](http://www.acamedbai.org.ar/iihema.php)

## IPFA/PEI 24th International Workshop on Surveillance and Screening of Blood-borne Pathogens

May 16-17, 2017  
Zagreb, Croatia  
Tel.: +31 20 512 3561  
Email: [info@ipfa.nl](mailto:info@ipfa.nl)  
[www.ipfa.nl/events](http://www.ipfa.nl/events)

## IPFA/BCA 3rd Global Symposium on the Future for Blood and Plasma Donations

September 11-12, 2017  
Atlanta, GA, USA  
Email: [info@ipfa.nl](mailto:info@ipfa.nl)  
[www.ipfa.nl/events](http://www.ipfa.nl/events)

## 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:

Michel Semienchuk, Editor  
*Hemophilia World*  
Fédération mondiale de l'hémophilie  
1425, boul. René-Lévesque Ouest, bureau 1010  
Montréal, Québec H3G 1T7 Canada  
E-mail: [msemienchuk@wfh.org](mailto:msemienchuk@wfh.org)

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The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of products to treat is prohibitively expensive for the majority of those affected with a bleeding disorder. The WFH is leading the effort to change this lack of access in developing countries by providing consistent and predictable access to treatment for all.

To learn more, visit  
[www.treatmentforall.org](http://www.treatmentforall.org)



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FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA