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Success down under

The WFH 2014 World Congress in Melbourne

/ Jens C. Bungardt, WFH DIRECTOR CONGRESS AND MEETINGS

The WFH World Congress in Melbourne, Australia wrapped up on May 15 and the overwhelming sense from the over 4000 attendees from 128 different countries was that the event was a complete success. For over two years, the WFH and its partner Haemophilia Foundation Australia (HFA) had been working right up to the last minute to ensure the event would be memorable.

The foundational success of Congress began with a substantial medical and multi-disciplinary program presented by leading experts in hemophilia and other inherited bleeding disorders. Among the many program highlights was the opening plenary by WFH president Alain Weill setting the tone for a new era when he announced several significant multi-year agreements for unprecedented donations of blood clotting factor to the WFH representing a major step toward meeting its humanitarian aid goal for developing countries.

Congress started on Sunday, May 11 with a series of professional development sessions run by the various medical and multidisciplinary committees of the WFH, where participants focused on important challenges in their respective fields and discussed ways to put new initiatives into practice.

Congress was officially launched that same evening with an opening ceremony that featured a lineup of distinguished guests from the Minister for Health from the State of Victoria, the Honourable David Davis, who welcomed the global bleeding disorders community to Melbourne, WFH patron Jan Willem André de la Porte,



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www.wfh.org



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the son of WFH founder, Frank Schnabel Jr, and 12 speakers representing the WFH global community from scientists and doctors to patients and advocates, who spoke of their experiences and hopes for the future.

While the previous Congress had focused on the 50th anniversary, the 2014 World Congress sought to cast an eye forward. This theme was central throughout the programs for the five-day event as each session spoke to how the community as a whole was moving forward toward the vision of treatment for all.

For HFA and its volunteers, Congress really opened their eyes to the global nature of the growing community. "I walked into the foyer and saw the flags from all the different countries," said HFA Executive Director Sharon Caris, "and I thought, 'Yes, this is a truly global organization.' People have been coming up to me and saying, 'Wow,' so many stakeholders have come together to make this work."

A TASTE OF AUSTRALIA

On top of the scientific content, the city of Melbourne provided a wonderful backdrop and excellent host for the 2014 World Congress. Delegates (when not in sessions) were able to enjoy some unseasonably warm fall weather in Melbourne. The facilities at the Melbourne Convention and Exhibition Centre (MCEC) were a perfect fit for Congress, allowing for open scientific discourse in a comfortable setting. The MCEC location in the centre of the city was ideal as it was close to a

host of bars, restaurants, and attractions for the after Congress hours sessions.

Attendees did not have to go far to enjoy a taste of Australia, when the World Congress played host to a fun-filled Aussie evening of entertainment in the form of costumed kangaroos, hissing king lizards, curious sea gulls, and alluring eucalyptus trees. The Taste of Australia event provided an excellent way for delegates to mingle with colleagues in a less formal environment and have a little fun in the process.

Congress was closed out on Thursday, May 15 with the farewell dinner. Delegates dressed in their best, dined on delicious fare and danced the night away.

GENERAL ASSEMBLY

At the WFH 2014 World Congress general assembly, representatives from 128 national member organizations listened carefully to presentations given by the Canadian Hemophilia Society (CHS) and the Hemophilia Society of Malaysia (HSM) in their bids to host the WFH 2020 World Congress. CHS was bidding to host the event in Montréal, while Malaysia wanted to bring the global bleeding disorders community to Kuala Lumpur. Both organizations argued well but in the end it was Malaysia that took the most votes.

The assembly was the perfect time to also welcome new national member organizations into the WFH. President Alain Weill

personally welcomed each of the new members at the assembly. Bolivia, Cambodia, Ethiopia, Libya, Maldives, Mali, Togo and Zambia now make up part of the 128 national member organizations that are a part of the WFH.

WORKING IN TANDEM

Overall, Congress left those in attendance with an overwhelming feeling of community. "For me, the feeling was best demonstrated where individual patients were willing, and sometimes keen, to share their personal experiences in a trusting and caring environment," said Jonathan Spencer, president of Haemophilia Foundation Tasmania, in an article published in HFA's July 2014 newsletter.

The WFH and our local hosts, HFA, thank all those of you that made the 2014 World Congress a resounding success. This success was reflected in the Congress evaluation forms, which were filled out post-Congress that gave the WFH 2014 World Congress the highest rating since evaluations were started in 2008. As a thank you for filling out the evaluation form the WFH offered up an Apple iPad to be won in a draw. The lucky winner was Professor Carl-Erik Dempfle of Mannheim Germany.

The 2014 World Congress provided participants the time to look back at all the accomplishments in the WFH's 50 years and to take that first step into the future, looking ahead at all the breakthroughs to come in our goal of treatment for all. We hope you will join us from July 24-28, 2016 in Orlando, USA, for the next WFH World Congress.

WFH 2016 WORLD CONGRESS

Orlando, USA · July 24-28

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PRESIDENT'S COLUMN

Patient empowerment key to the WFH comprehensive care model

/ Alain Weill, WFH PRESIDENT

At the WFH, we have always believed that patient empowerment can improve the quality of care for people with bleeding disorders across the globe.

So for us, the issue of patient empowerment is no different than that of humanitarian aid, where we needed to create a new universal paradigm to make possible predictable and sustainable aid. A few years ago, it was a notion that was difficult to realize. Yet with many of our partners already aligned with our philosophy and making the point that multi-year donations were possible, we pushed the envelope with the others to change their business models for humanitarian aid donations. And here we are.

Surely we can call on the same levels of collaboration to improve levels of patient empowerment around the world?

NOT STARTING FROM SCRATCH

Patient empowerment is already built into the WFH comprehensive development model, in both theory and practice. It is our cornerstone, with the patient and the patient's caregivers and family placed squarely in its centre. We

carry out our work in collaboration with our national member organizations, so there is never a 'one-size fits all' solution to any need that may arise.

Patients are both the recipients and providers of information and education, acting as advocates and leaders within their local communities.

For us, the question isn't what can we do to empower patients, the question is: what else can we do and with whom? Where can we bring our expertise, our network and our energy to bear so that people with bleeding disorders in both developed and developing countries feel they have the power of choice in the type and manner of health care they receive?

CHOICES THAT BEGET POWER

The variety of treatment products available today and the arrival of longer-acting medicine for people with hemophilia means patients won't be confined to one or two or even three options. They and their health care providers will have a choice. And they will have the power to decide how they want to manage their treatment protocol. That was unimaginable fifty years ago.



The younger generation of people with bleeding disorders will be able to make choices that previous generations, my son's included, could not. And that is their power, with health care practitioners and institutions, governments and their peers in this broad community.

Indeed, I would argue that it is the role of the WFH youth leadership to articulate what patient empowerment means to them, the role they want to play in their health care and how they want to work with their local health care practitioners, institutions and governments.

Because empowerment, like power, is something one takes; it is not something one receives.

WFH 2013 Annual Report available



The World Federation of Hemophilia 2013 Annual Report is now available. It truly was a banner year for the WFH as it celebrated its 50th year of helping to improve the care and treatment for people with inherited bleeding disorders around the world. In the report, you can read about several outstanding young people from the global community and how they are making a difference in the world. In the newly designed report you can also read all about the success and ways in which the WFH is working toward building a vision and a future of Treatment for All.

The report can be viewed or downloaded on the WFH website at www.wfh.org.

VP MEDICAL WRITES

Introducing the new WFH vice-president medical: Marijke van den Berg

/Marijke van den Berg, WFH VICE PRESIDENT MEDICAL

As this is my first column, I would like to introduce myself. At the start of my career I worked in adult hematology for three years before I switched to pediatrics to become a pediatric hematologist. After working many years as a pediatric hemato-oncologist, I decided to focus on hemostasis; and so from 1992 to 2008 I was the director of the Van Crevelde Kliniek, the Dutch National Hemophilia Centre.

After switching my career focus for four years working on the board of directors of a large teaching hospital I realized I missed hemophilia research dearly. Presently, I work as a senior investigator at the University Hospital in Utrecht and as the Director of the PedNet Registry, a collaboration of 31 hemophilia centres from 16 countries.

THE JOURNEY BEGINS

International collaborations are very important to improve the knowledge of rare diseases such as hemophilia. And if you attended the WFH 2014 World Congress in Melbourne, you'll understand what I mean.

My journey as VP-medical started, officially, at Congress. And it was a memorable one, as both the venue and the city added to the overall experience. Our local hosts and organizers, together with the WFH staff, did their utmost to have all this combined with a very interesting program. There was ample time to meet and interact with colleagues and friends. This is crucial for a conference such as ours, where the benefits are not only the dissemination of scientific knowledge but also the interaction between all disciplines involved in hemophilia care. Most importantly, of course, the WFH is a patient organization and so many people with hemophilia were involved in all aspects of the program.

The farewell event was a good example of what the venue was capable of: a wonderful dinner and a great party. For me and many others, to see so many young people dancing and having a great time, was a highlight of the evening:

this is what modern hemophilia care has made possible.

IMPORTANCE OF PROPHYLAXIS

In the Netherlands, we adapted prophylaxis very early and during my career as a hemophilia doctor I was able to observe the benefits of early prophylaxis.

I have seen many young children receive their diagnosis and the distress this gave to their parents. After the start of prophylaxis and the acceptance of frequent infusions, they feel that their life has come back. Bleeding is reduced to normal and children can be allowed to participate in regular activities without concern that they will develop abnormal joints.

In the Netherlands, like in many European countries, all treatment costs, both in the clinic and during home treatment, are completely covered by health insurance. Obviously, this helps parents and physicians to make the choice to start treatment regardless of the cost of clotting products.

The benefits of prophylaxis are many, and after finding their way with venous access, families and children experience a normal life, participating in the same activities as their peers. When venous access is indeed feasible, home treatment is given by the parents or by local health care personnel. This has made a huge difference, not only for the families but also for the supportive care provided by the hemophilia treatment centres. Treatment centres in the developed world have changed from providing mainly emergency care to becoming support and knowledge centres that focus on defining care for treatment complications, such as inhibitors and musculoskeletal problems.

Decades ago, WFH and WHO acknowledged that prophylaxis is the standard of care for all patients with severe hemophilia. However, it is still debated when to start and how to dose. Recent studies have demonstrated that 55 per cent of the children with severe hemophilia are born in families unaware of hemophilia. In these cases, the diagnosis is often made only after several bleeds, so that by the time of diagnosis patients have already had joint bleeds as well. Starting prophylaxis is a large step,



even more so for families without members with long-standing arthropathy. Patient organizations can increase awareness and help families cope with the need for frequent infusions. The biggest gain for patients is to prevent their joints from bleeding; and this must begin at the earliest age possible.

LOOKING AHEAD

It is with great enthusiasm that I support the initiative of the WFH and its partners in the collection of plasma and the development of products, so that we may have a sustainable donation program for countries that still have no treatment at all. Of course this can only succeed when governments are involved as well.

We all have embraced the main goal of the WFH in closing the gap. This means that we work hard not only to increase the number of patients that get a diagnosis, but also to make sure they will have access to clotting factor products and, eventually, prophylaxis to prevent bleeding and to improve their long-term outcome.

Are we able to deliver care and clotting products to many more patients? Can we introduce prophylaxis in children that presently have not received regular treatment? These are the most important questions for me in the coming years and I hope with all our efforts together we will be able to answer them with a resounding yes!

WFH Humanitarian Aid Program provides greater choice

One of the bigger news items to come out of the WFH 2014 World Congress was the announcement that WFH partners had committed to donations totalling 700 million+ IUs of treatment products (see page 10). Equally big news was that 500 million IUs, donated by Biogen Idec and Sobi, would be longer-acting and have a longer shelf life.

/Anna Maria di Giorgio, WFH INTERIM DIRECTOR COMMUNICATIONS AND MARKETING

To understand the impact of the size and variety of the donations, one needs to step back and look at how the WFH's Humanitarian Aid Program began in 1996.

"At the time, we were able to address emergency bleeds only," said Assad Haffar, deputy programs director. "Our donations would be used primarily for life-threatening abdominal or inter-cranial bleeds."

They were also used to provide concentrates for WFH development programs and support efforts by the WFH and NMOs to lobby governments for ongoing purchases of these products and sustainable hemophilia care. The donations could not be used for corrective surgery. Someone with a bleeding disorder needing corrective surgery would require an average 80,000–120,000 IUs for the surgery and subsequent support until full recovery. "That just wasn't tenable for us at the time," said Haffar.

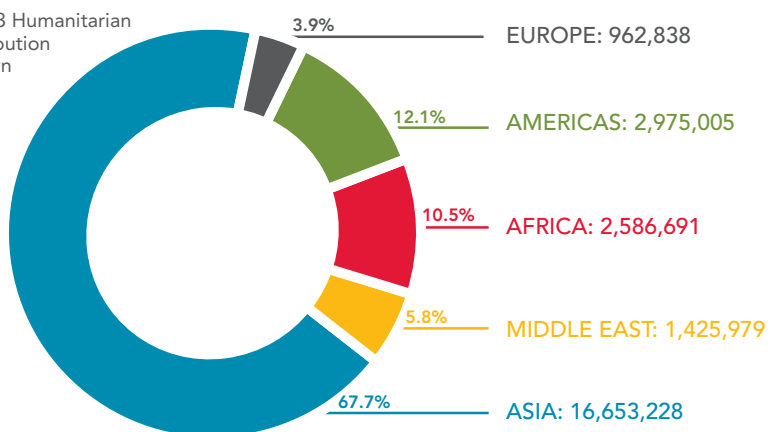
"Over time, donations from corporate partners increased and sometimes came in larger assays, vials holding 3000 or 3500 IUs. When they also had a limited shelf life, they were perfect for corrective surgeries," said Haffar.

LARGEST GLOBAL SUPPLY CHANNEL

Since 1996, the WFH has distributed 224 million units of factor to 82 countries and is now the world's largest supply channel of donated hemophilia treatment products. The WFH receives donated products from product manufacturers, treatment centres and homecare companies. Products are sent to registered hemophilia treatment centres or to recognized national hemophilia organizations.

Global distribution of treatment products is a massive task and involves the WFH's extensive global network of member associations. Most donations are secured and distributed in collaboration with WFH USA

WFH 2013 Humanitarian Aid distribution breakdown



and the invaluable assistance of Hemophilia of Georgia, a not-for-profit organization in the United States, and the Irish Haemophilia Society. Several corporate partners have supported the Humanitarian Aid Program over the years including Baxter, Bayer, Biotest and others.

GAME CHANGERS

Multi-year commitments offer a sustainable solution for predictable humanitarian aid in developing countries.

The first corporate partner to offer a multi-year donation to the WFH Humanitarian Aid Program was CSL Behring, in April 2009. The company pledged 2 million IUs of factor VIII concentrate, with a minimum one-year shelf life, over a period of three years. Six months later, Wyeth committed to 40 million IUs of recombinant factor therapy, the largest such donation in the Program's history. And Grifols made a three-year commitment of 60 millions IUs over three years. Both events set in motion a new game plan for both the WFH and its corporate partners.

Today, with a total of close to 1 billion IUs donated over multiple years, and with the donations varying from plasma-derived to recombinant therapy to new longer-acting products, governments and NMOs in need can choose from a variety of treatment options for their communities. Add to that Project

Recovery and Project Wish (see page 8), and the picture becomes even more promising.

ENVISAGING NEW POSSIBILITIES

From a humanitarian health care perspective, larger and predictable donations mean the WFH can envisage addressing the needs of children under five years of age as the Biogen Idec and Sobi products were designed for prophylaxis.

Haffar explained: "If we are able to administer prophylaxis to toddlers in their first two years of life, low or intermediate doses of treatment will prevent disabilities or other problems in their joints."

This is a critical age according to Haffar, who recognizes the WFH is on new territory with this possibility.

"We are now in a position to be able to consider providing humanitarian aid for prophylaxis in children, and using this product for surgeries and acute bleeds. We will be able to reach horizons we could never reach before for children and people needing corrective surgery," he said. "Added to what we already provide through the Humanitarian Aid Program, we have a more complete range of options to work with and offer NMOs and governments."

WFH launches Professional Membership at 2014 World Congress

Professionals now have a new membership option that was launched in May during the WFH 2014 World Congress.

/Marlene Spencer, WFH MEMBERSHIP AND DEVELOPMENT COORDINATOR

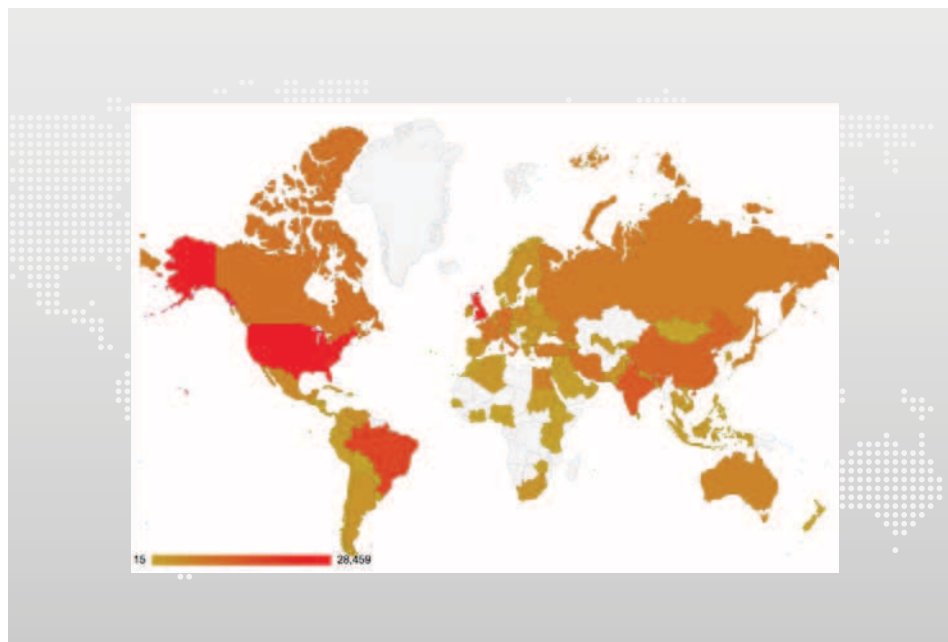
This new category of membership is designed to meet the needs of the doctors, scientists, researchers, caregivers, and other professionals involved in the global bleeding disorders community. It offers additional value and new and enhanced access to WFH resources.

Exclusive to this new category of membership is online access to *Haemophilia*, the official journal of the WFH, access to webcasts of some of the most exciting talks at the WFH 2014 World Congress, and over 300 WFH publications in six languages and much more. The professional category of membership joins together an ever increasing network of scientists, researchers, doctors, caregivers or indeed anyone who has an interest in latest scientific research about bleeding disorders.

As an incentive, delegates signing up or renewing for any category of WFH membership, or upgrading to the new professional membership at Congress were entered in a daily draw for a chance to win a one year print subscription to *Haemophilia*, the official journal of the WFH. Congratulations to Cheryl Ellis, Australia, Anne Goodeve, United Kingdom and Miryam Parreira, Argentina.

The grand prize draw winner was Sylvia Thomas, from Brazil, who won a free registration to the WFH 14th *International Musculoskeletal Congress* in 2015.

For more on WFH membership visit www.wfh.org/membership.



Twelve years of global data now available online

The WFH has launched a new, interactive online tool for reporting data on people with bleeding disorders collected via the Annual Global Survey. This online resource, which allows users to look through over ten years of statistics, was launched at the WFH 2014 World Congress in Melbourne.

/Hyun Song, WFH EDUCATION AND PUBLIC POLICY ASSISTANT

Since 1999, the WFH Annual Global Survey has gathered selected demographic and other information about people living with hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders throughout the world.

Over the years, the survey has developed into a sophisticated system with features that have significantly improved the quality and accuracy of the data collected. The new system allows users to search for the information they need to support advocacy, lobbying, or research purposes and to create and customize graphs to display that information in a visual, impactful way. For example, users can consult a world map illustrating the global prevalence of bleeding disorders, or graphs that show the distribution of bleeding disorders by age group. They can also look at the use of factor products in different

geographic regions to gain an overview of the global availability of treatment.

Thanks to its continuing partnership with national member organizations, the WFH has been able to paint a global landscape of people living with bleeding disorders and the availability of care and treatment needed to improve their lives.

With the data collection program and this new interactive online tool, now available on the WFH website, the WFH hopes to give the bleeding disorders community—including patients, researchers, clinicians and industry stakeholders—a fresh perspective on the global impact of bleeding disorders as well as a valuable insight into the improvements in access to care that have been made.

To browse the WFH Annual Global Survey data online, go to www.wfh.org/globalsurvey.

Project Recovery shipments reaching those in need

Shipments of factor VIII manufactured as part of Project Recovery have started arriving at treatment centres around the world. These are the first deliveries in a project that the WFH and its collaborators have worked on for over a decade.

/Mark Brooker, WFH SENIOR PUBLIC POLICY OFFICER

Moving forward, this reliable supply of factor VIII will allow the WFH to carefully plan its Humanitarian Aid Program donations and ensure efficient use of this valuable gift. It also serves as an example and inspiration for embarking on similar humanitarian projects with other countries where there is more unused factor VIII.

There are a few reasons for the existence of “surplus” factor VIII in some parts of the world. In countries where most of the patients use recombinant clotting factors, there is not as much demand for plasma-derived factor VIII as there was in the past. At the same time, there is an increasing demand for another medicine derived from human plasma – immune globulins (IG). This means that more and more plasma is collected to manufacture IG but the factor VIII is not all manufactured into final products because it is not needed

domestically. Given that there is a shortage of clotting factors in many parts of the world, it is unfortunate that much of this surplus goes untouched.

The idea first proposed by the Canadian Hemophilia Society (CHS) was simple—Canada has surplus cryoprecipitate that is discarded rather than purified into factor VIII, why not process it and donate it to help patients in need in other countries? CHS took this proposal to Canadian Blood Services (CBS) and WFH and Project Recovery was launched. However, what seemed so simple turned out to be very complicated. Every step in the process—from blood donation to delivery of the finished product—had to be evaluated.

Grifols, the company that harvests the cryoprecipitate, agreed to perform additional tests on the plasma to comply with European regulations. Once Biotest (the manufacturer of the final product Haemoctin) joined the



WFH president Alain Weill holding up the first veil from Project Recovery.

project, they made an enormous effort to make Project Recovery a reality. With four partners and three different countries involved, the details sometimes seemed overwhelming. Thanks in large part to CBS and Biotest's firm commitment and humanitarian vision, unused Canadian factor VIII is now available to patients around the world.

At the World Congress in Melbourne, WFH president Alain Weill announced an agreement with the Italian blood services to begin work on a similar project (Project WISH) using surplus Italian factor VIII. This will also result in a sustained long-term supply of clotting factor for humanitarian purposes. Furthermore, the WFH held talks with officials from other countries interested in finding ways to make their surpluses available to people in need. There is enormous potential in “surplus” clotting factors and the success of Project Recovery demonstrates that it is possible to get them to the people who need them most.

Webcasts, posters, and panel discussions: WFH 2014 World Congress educational resources

/Fiona Robinson, WFH EDUCATIONAL MATERIALS MANAGER

The WFH is pleased to offer access to webcasts of selected sessions from the WFH 2014 World Congress program to Congress delegates and WFH members. The webcasting service enables you to view full media presentations with animated slides, reproduction of the speaker's laser pointer movements, and embedded videos. For selected talks, PowerPoint slides are also available to download at www.wfh.multilearning.com/wfh.

The webcasts are also available on Apple and Android mobile devices via “TALKS on the GOTM”. Please visit www.talksonthego.com or download the application through the Apple Store or Google Play store.

Over 400 WFH Congress 2014 posters are publicly available (in English) in our online gallery. The user-friendly carousel-style display offers options such as searching, downloading, and sharing posters; emailing the poster author directly; as well as open discussion forums. www.postersessiononline.eu/pr

In an exciting new development this year, the WFH capitalized upon the gathering of great minds offered by Congress, to record lively panel discussions between key opinion leaders on several topics of great interest to the inherited bleeding disorders community. Congress delegates and WFH members can watch past WFH presidents, leading hematologists from around the world, people with hemophilia, and members of the



Plenary speaker Manuel Carcao

multidisciplinary care team trade views on the evolving treatment landscape of hemophilia, issues around treatment adherence, and the pros and cons of mandatory treatment diaries. These discussions are hosted at the same website as the webcasts: wfh.multilearning.com/wfh



Johanna Overstreet and family



Chetan playing soccer

A story of survival

When Johanna Overstreet and her husband decided to adopt a child with medical needs, they were prepared for it to be a difficult process, but believed they were capable of providing a home for a child who would need constant treatment. “We had sought to adopt a medical needs child, since my training as a nurse allowed us to handle things others might be scared to take on,” Johanna explains.

/Vanessa Herrick, WFH COMMUNICATIONS MANAGER

When a young boy in India who had severe hemophilia B was put up for international adoption they began the long adoption process and faced particular challenges due to his having hemophilia. Overstreet is a trained nurse, and her husband has von Willebrand disease, so they were confident they could provide everything that the little boy, named Chetan, would need in a family, but there was little precedent for the adoption. “India had never placed a child with hemophilia for adoption. We were interviewed by the embassy and there was an article in the *Times*, it was a really big deal for them to be placing him,” she says.

A ROUGH START IN LIFE

Born in India, Chetan’s mother died in childbirth, leaving his father to raise two young children on an impossibly low salary. Despite the difficult circumstances he made an effort to take care of his children. In the first years of Chetan’s life his father placed him in a nursery school, the Indian equivalent to daycare, where he was kept in a crib for the majority of the time. Despite a lack of activity it quickly became apparent that Chetan had medical issues as he visited the hospital six times from the age of 20 months to just before his third birthday, often with a cut lip or a nose bleed that would not stop. Eventually, two months before he turned three, a doctor noticed what

appeared to be a joint bleed in his toe and it led to the blood test that showed a severe factor IX deficiency—hemophilia B.

The doctor told his father that Chetan would need treatment for the rest of his life. “He was told he would need to take Chetan to the hospital once or twice a month for fresh frozen plasma as it was the only treatment available,” Overstreet explains.

The prognosis from the doctor made Chetan’s father decide that he had no choice but to give him up to Ashraya orphanage in hopes of placing him with a family that could afford to care for him properly. Within a week of being released from the hospital, Chetan was surrendered to the orphanage. His father was so distraught by giving up his son that he had to be carried from the building.

Chetan spent months in the orphanage with his father calling every few weeks to get news on whether he had found a home. When it was confirmed that a family from America was to take him in, he never phoned again. That was the last anyone has heard from Chetan’s father, but Overstreet thinks of him often “I believe that he put Chetan in the orphanage to make sure he got the medical treatment he needed,” she says.

Overstreet was concerned about how Chetan was going to be cared for in the six to nine months that the adoption would take as the orphanage had no experience or training

dealing with a child with hemophilia.

Thankfully, the special needs coordinator for the adoption agency was not only a social worker, but had been a nurse previously. Overstreet explains how she ensured that Chetan would remain as healthy as possible before going to his new family. “She had contacted the Hemophilia Federation of India, who had in turn contacted the World Federation of Hemophilia. They agreed to provide my son with Benefix until he traveled stateside.” Overstreet is confident that the donation saved her son’s life.

As the adoption was nearing completion, Chetan suffered a series of brain bleeds and was taken back to the hospital where he had been treated many times before. The hospital ran the required tests needed to confirm that he was indeed bleeding in his brain and confirmed it with Johanna. She was overwhelmed that a week away from her arriving in Bangalore to bring Chetan home they were facing what she believed to be a worst case scenario. “We had just had the call that he was coming to us and then we got a call saying he was probably going to die. It was pretty much as bad as it could get.”

Or so she thought.

Two days later on December 26, 2004, an earthquake hit just beneath the Indian Ocean off the coast of Sumatra.

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WFH Humanitarian Aid Program receives major donations

/ Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

At the WFH 2014 World Congress in Melbourne, WFH president Alain Weill announced the donation of more than 700 million IUs of factor from corporations that have answered the WFH global call to action that was first given at the 2012 World Congress in Paris.



These generous contributions have made the WFH the world's largest supply channel for donated hemophilia products. Since 1994, WFH's Humanitarian Aid Program has distributed 248 million IUs of product in 86 countries, helping about 90,000 people with bleeding disorders.

And yet, said WFH president Alain Weill during Monday's plenary session, 75 per cent of people around the world who have bleeding disorders still don't receive appropriate care.

Thanks to the generosity of corporate partners and, in a particular, a new, groundbreaking agreement with Biogen Idec and Sobi, that number may soon decrease.

On May 13, Weill announced that these manufacturers have agreed to donate 500 million IUs of factor VIII and factor IX over the next five years to WFH's Humanitarian Aid Program. "That's 500 million IUs of prolonged half-life treatment products," Weill said.

Biogen Idec and Sobi join two other manufacturers that made significant, multi-year treatment product donations that same month: CSL Behring and Grifols.

In 2009, CSL Behring was the first WFH partner to commit to annual donations, and it has renewed its agreement for another three years. Grifols has also made a three-year commitment to deliver 60 million IUs of product.

Sobi CEO Geoffrey McDonough said his company made its donation both to increase the amount of product available and to ensure a more consistent supply.

In the long run, said Biogen Idec CEO George A. Scangos, PhD, "our sincere hope is that this initiative will inspire others to step up their donations as well."

The first vials of the new product from Biogen Idec will be available for shipment in the second half of 2015.



GLOBALFEAST

A familiar and yet all-new way to support the World Federation of Hemophilia

Get together with friends, family and your whole community, to raise awareness about bleeding disorders and raise funds for the WFH mission.

- Create your own fundraising and event page as part of the WFH site.
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- Set your personal fundraising goal and see your progress in real time.
- Import your contacts, post to social media and send email appeals directly from your personal Global Feast dashboard.

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Or on our Facebook page at www.facebook.com/wfhemophilia

Former CEO John E. Bournas hopes to have left a lasting mark

Although his tenure with the World Federation of Hemophilia (WFH) was brief, former CEO and executive director John E. Bournas has left a lasting impact on the organization and the community as a whole.

/ Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

Since joining the organization in 2012, Bournas has led the WFH with a unique vision, on the one hand pushing industry partners to contribute more towards the WFH vision and on the other enabling the WFH and its members to reach out to the wider community and help the millions of people that still are undiagnosed and that go without treatment.

For Bournas it was always about the patient. “What initially drew me to the organization was clearly its capacity building and its humanitarian focus. I had always, for a very long period of my professional career, wanted to give back and to work in a patient-based organization; so when the opportunity arose I just decided to take it and be able to lend the professional skills I had developed along my career to leverage that to the benefit of patients.”

When Bournas joined the WFH in 2012 he found an organization that was meeting its mandate and doing so in an effective manner but there was room for improvement. “I think successful organizations are based on good communication, innovation and a lot of teamwork, so that’s what I attempted to do and hopefully I have been able to instill these values in the organization so that it may have that type of mentality going forward.”

Working in an organization that has access to essential medicines around the world at the forefront of its core values was a strong driver for him. Born in the developing world, Bournas spent a good amount of his life travelling and living around the world. He has borne witness to the imbalance in care that exists between developed and developing nations.

COMING TO FRUITION

When pressed to name one accomplishment that stands out for him, Bournas did not hesitate in mentioning the fruition of the recent humanitarian aid projects that were announced at the WFH 2014 World Congress and that were delivered through strong partnerships. Those projects are Project Recovery, the initiative between the WFH, the Canadian Hemophilia Society, Canadian Blood Services, and Biotest to take unused blood product and turn it into life-saving factor; Project Wish, the program developed by the Italian Centro Nazionale del Sangue that sees donated blood go directly to where it is needed most, plus the announcement of several major commitments by corporate partners that could see over 500 million IUs of factor go into the Humanitarian Aid Program.

“I think if 20 years from now a mother in a developing world has children with hemophilia and they are able to hold them, embrace them, and to think that 20 years prior there was a group of people in Montréal that decided to work on this, decided to make this project a reality so those children could have the medications they need, I think I would be happy with that,” said Bournas. “That gives me a lot of personal satisfaction and the reassurance that the time I have worked here with this group of people has been truly meaningful.”

His biggest regret as CEO of the WFH comes in not being able to get out of the office more and meet the people that make up the global community of the WFH. Bournas looks back on the times when he was able to visit a national member organization with affection and a strong sense of the reality of the conditions those with bleeding disorders must face on a daily basis. “It really had an impact on me as a person; and as a professional it just kind of reaffirmed the fact that if more



treatment is extended to people, they can lead normal lives.”

Although he leaves the WFH, in his nearly three-year tenure as executive director and CEO, Bournas has strengthened the core of the organization and grown its ability to meet the vision of treatment for all, helped bring about the WFH’s Research Program, increased the donations to the Humanitarian Aid Program ten-fold, pushed for a greater focus on youth and women with bleeding disorders and delivered a balanced budget in 2013, bringing the WFH to its first ever \$5 million revenue milestone in one annual year.

A FINAL THOUGHT

All great accomplishments to leave behind with a head held high.

“I am very grateful for the opportunity that has been given to me. I am very thankful for the friendships that I have established. I would like to keep reciprocating the kindness that has been shown to me by many people with inherited bleeding disorders around the world. I am thankful for all the dreams they have shared with me, the hopes, and their wishes for improved living conditions for themselves, their family members. I will still be working in the field of drug shortages, I won’t be that far, and I will still have the patient view and the patient perspective in mind. The advocacy will continue.”



Global volunteers recognized at WFH Awards Ceremony

At the 2014 World Congress in Melbourne, the WFH took some time to recognize some of the outstanding volunteers who are the cornerstone of its global community.

/Marlene Spencer, WFH MEMBERSHIP AND DEVELOPMENT COORDINATOR

The ceremony held at the Melbourne Convention and Exhibition Centre was emceed by Aris Hashim and started with a few opening words from CEO John E. Bournas and WFH Patron Jan Willem André de la Porte.

The Christine Lee Haemophilia Journal Award is named in honour of Prof. Christine Lee, who founded *Haemophilia* journal in 1995 and was inaugurated at the WFH 2012 World Congress in Paris. The award is given to a young researcher in recognition of a published article in *Haemophilia* that receives wide recognition and support from the scientific community. At the awards, the WFH recognized the 2013 winner **Susanna Lovdahl** (Sweden) for her published paper, *Incidence, mortality rates, death in haemophilia patients in Sweden*. The 2014 winner was **Laurens Nieuwenhuizen** (Netherlands) for his paper—*Identification and expression of iron regulators in human synovium: Evidence for upregulation in hemophilic arthropathy compared to rheumatoid arthritis, osteoarthritis, and healthy controls*.

Magdy El-Ekiaby (Egypt) was the winner of the 2014 Inga Marie Nilsson Award, sponsored by Octapharma, given to an individual or pair of WFH volunteers who best contribute to develop hemophilia care through their own initiative and for contributing new ideas

and projects. There are many instances of Magdy's leadership in the community, from his participation in workshops, symposiums, and outreach programs around the world to his involvement with many WFH programs, all done with grace and humility.

The 2013 Pietrogrande Prize was awarded to **Dr. James Luck**. This prize is given to a health care professional who has made a significant contribution to furthering the mission of the WFH Musculoskeletal Committee.

The Henri Chaigneau Award of the Association française de hémophiles was awarded to **Professor Alan Thomas Nurden** for his lifelong major scientific contributions to the understanding of platelet pathologies mechanisms present in rare congenital bleeding disorders.

The Twins of the Year Awards are given out annually to the organizations or treatment centres that best showcase the philosophy and potential behind the Twinning Program. The program pairs hemophilia organizations and treatment centres in developing and developed countries to encourage the transfer of skills, knowledge and information.

The Hemophilia Treatment Centre Twins of the Year for 2012 are **National Institute of Hematology in Hanoi, Vietnam and the Blood Transfusion and The Alfred in Melbourne, Australia** and for 2013 the award is shared between **Davangere Hemophilia**

Society, India and Liverpool Paediatric Haemophilia Society (UK) and Christian Medical College, Ludhiana (India) and the Henry Ford Hospital (USA). The Hemophilia Organization Twins of the Year for 2012 went to **the Vietnam Society of Congenital Bleeding Disorders** and the **Irish Haemophilia Society and The Hemophilia Association of Mauritius and South African Haemophilia Foundation** in 2013.

The Susan Skinner Memorial Fund for 2014 was awarded to **Salma Karan** of Pakistan and in 2013 it went to **Leslie Situ Ferber** from the USA. Both Salma, who is a nurse and has von Willebrand disease, and Leslie, a carrier and passionate advocate, best exemplify the young women who demonstrate leadership in their communities.

As part of the Advocacy in Action Program, funded by Baxter, the Advocacy Recognition Award was given to the **Fundacion de la Hemofilia de Argentina, filial Cordoba** in 2013 and the **Polish Hemophilia Society** in 2014. Both organizations successfully implemented steps learned from the program and helped to sustain and improve care for people with bleeding disorders in their country.

Launched in 2013, the WFH Clinical Research Grant Program is a peer reviewed program that helps provide support for international clinical investigation relating to inherited bleeding disorders. The programs awards



up to four grants per year for the best proposals that address critical issues of broad international significance. The 2013 recipients of the grants were **Roger Schutgens** and **Lize van Vulpen** (Netherlands), *Joint distraction in the treatment of hemophilic ankle arthropathy*; **Kevin Deschamps** and **Sebastien Lobet**, (Belgium) *Quantifying foot biomechanics in haemophilic children with ankle arthropathy through an integrated approach*; **Paula James** (Canada) *Validation of the self-BAT in hemophilia carriers*; **Thomas Hilberg** and **Steffen Kruger**, (Germany) *Pain profile in people with hemophilia*.

Riten Kumar, Janneke I. Loomans, Yvonne V. Sanders, Hamideh Yadegari, and Jane Young where all awarded the WFH Young Researcher Award for their highly rated abstracts on hemophilia and other inherited bleeding disorders. The winners are selected from principle presenters and authors of abstracts submitted for Congress.

The emotional moment of the award ceremony came with the announcement of the International Healthcare Volunteer Award that honours a volunteer health care professional who has helped contribute to the vision and goals of Treatment for All. **Kevin Rickard**, a native Melbournian and a dedicated hematologist, deservedly won the award for his lifelong service to the bleeding disorders community. Professor Rickard was clearly moved and spoke passionately about his work and what the award meant to him. Rickard received a standing ovation from the audience as he walked off stage.

The Lifetime Achievement Award went to **Gordon Clarke** for his life-long commitment to securing a better treatment and care for people with bleeding disorders in his Northern Irish community and internationally with his involvement with the WFH. Unfortunately, Gordon was not able to join us

in Melbourne; however he expressed sincere thanks for the honour bestowed upon him as a recipient of this award. The award will be presented to Gordon in person by WFH president Alain Weill at an upcoming meeting.

The most prestigious WFH award was given to **Brian O'Mahony** and **David Page** who shared the International Frank Schnabel Volunteer Award for their contributions to furthering the mission and goals of the WFH. Both men have been tirelessly working to improve treatment and care for the bleeding disorders community across the globe and have been working alongside the WFH in various capacities for many years.

A special thanks goes out to Aris Hashim, Chair of the Awards Committee, for emceeding the ceremony. The WFH congratulates all 2014 award recipients.



Professor Kevin Rickard

50

Haemophilia journal special 50th anniversary edition

In May 2014, the WFH published a special 50th anniversary commemorative issue of its official medical journal *Haemophilia*. In this special edition, editors C.A. Lee, A.M. Street and E. Myles gathered some of the most important and interesting historical papers that chart how advances in the general understanding of hemostasis have resulted in dramatic improvements in the treatment and care for people with an inherited bleeding disorder.

The issue begins with an excellent overview on the history of the WFH from its founding through the blood crisis in the 1980s to today, written by former WFH president Mark Skinner and WFH chief operations officer Elizabeth Myles. In addition, the issue boasts several reprinted articles from older issues of *Haemophilia* that take the reader back through some of the most important historical moments and developments in the treatment of hemophilia.

This limited print run of *Haemophilia* is also available online at www.haemophiliajournal.com.

The WFH would like to thank Wiley Blackwell for the production of this special edition.

South Africa and Mauritius: WFH first African regional Twins

/Christine Herr, WFH INTERIM PROGRAM COORDINATOR, TWINNING AND GLOBAL NMO TRAINING

Although the Twinning partnership between South Africa and Mauritius officially started in 2013, the two organizations started working together in 2009. The partnership began when the South African Haemophilia Federation (SAHF) visited the Haemophilia Association of Mauritius (HAM) and saw the potential of the young Mauritian association to grow and to better serve the bleeding disorders community in the small African nation.

Where Mauritius is now in their development so too was the SAHF once. However, a Twinning partnership with the Canadian Hemophilia Society (CHS) that started in 2005 led the SAHF to make changes in how it approached bleeding disorders care and advocacy. Since the closure of this partnership, SAHF has made great strides in South Africa.

“We recognized that we could follow a similar process and adapt what we had learned during the Twinning with CHS for Haemophilia Association of Mauritius,” said SAHF President Bradley Rayner.



Twinning partners from South Africa and Mauritius pose for a photo during a workshop.

Armed with the capability and knowledge from their Twinning with Canada, SAHF was the perfect fit to help the Mauritian hemophilia society attain better levels of care.

“Although Mauritius has some basic treatment for people with hemophilia, it was not adequate,” said Asraf Caunhye, President of HAM. “Treatment was done through plasma and cryoprecipitate and care infrastructure was non-existent. The assistance from SAHF came at the most opportune time to meet the needs of Mauritius.”

From the outset of the Twinning between the two African nations the goals were clear. To raise awareness of bleeding disorders amongst the general public as well as government officials; to develop a strategic plan; to raise awareness and adopt advocacy skills; to establish a dedicated team of bleeding

disorders professionals to assist in the training of care givers; and to ensure all people with bleeding disorders in Mauritius have the chance to lead a normal life.

Although it has been just under a year since the Twinning Program began between HAM and SAHF, the partnership is already beginning to pay dividends. The Mauritian association has already developed a clear mandate to move forward with, has begun to establish ties with government officials, private sector companies and media outlets, and regularly meets with parents and patients to keep them informed of the latest news.

This successful collaboration led the WFH to award both organizations the Hemophilia Organization Twins of the Year Award in 2013.

The Twinning Program is supported by exclusive funding from Pfizer.

Macedonia and USA: Twinning helps to achieve new success

/Christine Herr, WFH INTERIM PROGRAM COORDINATOR TWINNING AND GNMO TRAINING

While Macedonia and Arizona may be over 10,000 kilometers away from each other, the WFH Twinning Program has shortened that distance through a common goal of capacity building for the Macedonian patient organization.

According to the WFH Annual Global Survey data from 2012, there are 315 identified patients with hemophilia in Macedonia. The Civil Hemophilia Association of the Republic of Macedonia, also known as Hemolog, was established to respond to the needs of the bleeding disorder community and in 2013 they celebrated their 15th anniversary. While Macedonia is classified as a middle-income country, there remain areas in the treatment and care of hemophilia patients that

require support and development. Hemolog Macedonia recognized the need to improve their organizational structure, fundraising initiatives and communication skills. This is where the support from Arizona has been invaluable. The Arizona Hemophilia Association (AHA) started in 1967 and with 47 years of experience they are well equipped to transfer skills and knowledge to international partners.

Collaborating on fundraising was a priority for the partnership. AHA is well versed in funding strategies and hosts a fundraising conference each year. These best practices were brought to Macedonia where they could be applied within a local context. The president of Hemolog, Marija Nakeska, said the biggest impact of the partnership was receiving fundraising support. In one word, Marija said Hemolog is now much “stronger.” Having fundraising skills

allows Hemolog to operate independently and build sustainable support for their community. This has also been a learning opportunity for AHA to view fundraising from a new perspective. Teri Morrison, the assistant executive director, said working within the Macedonian context has allowed AHA to find “new and creative ways to provide these resources” to our Twinning partner.

The next step in the partnership is outreach activities. With 40 per cent of the Macedonian population living in a rural area, developing strategies to bring awareness and education to these hard-to-reach populations is essential. As the partnership enters its fourth year in the Twinning Program, AHA and Hemolog will continue to work in solidarity to build a stronger hemophilia community.

The Twinning Program is supported by exclusive funding from Pfizer.



Vaughn Ripley: Man in motion

When Vaughn Ripley heard about the *Men's Health* Ultimate Guy fitness competition he joked to his family that he should enter. As a devoted health advocate and trainer, it was not an absurd idea that he would be considered for the top prize and featured on the magazine's cover.

/Vanessa Herrick, WFH COMMUNICATIONS MANAGER

What makes his story unique is that Ripley's motivation to enter was not to raise his personal profile in the health and fitness world but to raise awareness and advocate for two other communities to which he has a deep connection. The first being that he was born with mild hemophilia A and the other community he learned he belonged to during the tainted blood scandal that broke in the 1980s when doctors told him he had less than two years to live.

He was just 17 years old when he learned he had been infected with the HIV virus from a blood transfusion. "My doctor could not look at me when he told me. He stared at the floor," he remembers. "He finished with... and you have less than two years to live. It was devastating to hear, especially as a teenager."

CHOOSING A POSITIVE LIFE

The impact of his HIV positive status had serious implications for Ripley and his family. "We were all in shock. Because of the stigma we were afraid to discuss it outside of the family. When neighbors did find out, we started receiving crank calls and even death threats. Someone even threatened to burn our house down if we did not move out of the neighbourhood and our community swimming pool kicked me out. It was a tough time for sure."

The following years were a very dark time and Ripley credits his then girlfriend and now wife with helping him through it. When asked about having outlived his prognosis by

nearly two decades and his approach to life, he recognizes that facing death opened his eyes to living "with more zing!"

"I am a born fighter and I see life as a battle at times. This excites me and motivates me to try even harder." His secret to healthy living and dealing with both his HIV and his hemophilia is what Ripley calls his survival pie. "It is my belief that you must do a combination of things to live through, survive and thrive despite a life-threatening illness. Survival pie is essentially a balance of family, work, fitness, good nutrition, meditation, spirituality, positive thinking, surrounding yourself with positive friends and daily gratitude."

Ripley has developed his health regimen over the past two decades and is often approached by others looking for health advice. "I constantly get questions from the bleeding disorder community, people looking for advice on training as it can really curb bleeding episodes." He started writing blog posts but it felt restrictive to try and "pack it all into one post." He sees the value in blogging but realized that videos would be more efficient and instructional.

"It would give people a real visual sense of what I am talking about. My thought was a video would be more powerful and YouTube provides a perfect forum. You can upload videos for free and they are available to folks for free."

PAID FORWARD AND BACK

The idea of access appeals to Ripley and while he is aware that he could have created DVDs

that focus specifically on joint health and marketed them, it did not sit well to charge a fee when the motivation behind the project is to help others. He has developed outlines for 18 videos and will begin to shoot and upload them to YouTube soon.

Ripley may be feeling particularly indebted to the community these days after the extraordinary amount of support he was given after deciding to make the leap and enter the *Men's Health* competition. "I had no idea that so many people in the hemophilia and bleeding disorders community would step up and vote for me."

GETTING OUT THE MESSAGE

Ripley not only entered the Ultimate Guy competition, he held first place in the public voting for two months straight and even had other competitors contact him and tell him they were rooting for him. "It was humbling. And awesome!" He accumulated over 15,000 online votes.

While Ripley did not win the competition, the editor of *Men's Health* felt his story was compelling enough for a profile article in their upcoming November edition.

When asked what advice he would pass on to a young person with a bleeding disorder Ripley speaks from the heart as he has a young daughter with mild hemophilia A. "Break free of the chains that would have you believe that you are disabled or incapable of doing great things. The sky is the limit for people and you are no different."



World Hemophilia Day 2014

Vanessa Herrick, WFH
COMMUNICATIONS MANAGER

On April 17, World Hemophilia Day, the global bleeding disorders community joined together to raise awareness, to celebrate who they are, and to Speak Out: Create Change for the millions of people around the world living with a bleeding disorder.

As part of the Speak out: Create Change campaign the WFH created five different online infographics that were posted to the WFH Facebook page (and are still available). The infographics provided important information on key issues for the community to comment on and like and share with their online network. Some of the issues that were addressed were the qualities of a good leader, symptoms

in women with a bleeding disorder, and the importance of fitness in those with a bleeding disorder.

The infographics were incredibly popular with the WFH online community. The infographic depicting the symptoms of a bleeding disorder in women was the most liked and shared.

The WFH also hosted an online photography competition with the theme *UR1in1000* that asked people to share their photos that demonstrate what it is about them that makes them unique. The dozens of photos from across the world can still be seen on the Facebook page.

This year's World Hemophilia Day was also exceptional as it marked a series of particularly important landmarks being lit red to help raise awareness amongst the

general public about the issues facing the bleeding disorders community. The world-famous Niagara Falls' waters were lit red on the US and Canadian sides, as well as the CN Tower in Toronto, Ontario, Langevin Bridge in Calgary, Alberta, the AAMI Park at the Olympic Parks in Melbourne Australia, and the Leonard P. Zakim Bunker Hill Bridge in Boston.

It is the WFH's hope that this unprecedented support spreads to all corners of the globe and that in 2015 even more global landmarks shine red on World Hemophilia Day.

The WFH is grateful to Bayer, Baxter, Biogen Idec Hemophilia, CSL Behring, Novo Nordisk, Precision Biologic for funding support of World Hemophilia Day 2014.





celebrated around the world



PHOTO COMPETITION

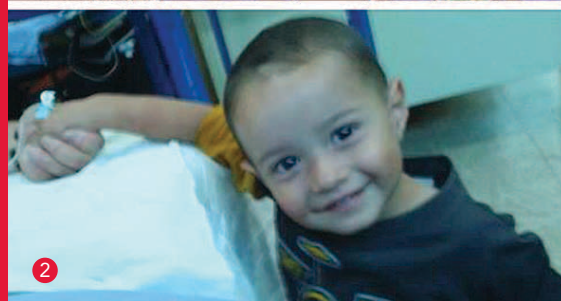


PHOTO COMPETITION WINNERS:
 1. First place photo contest winner Bojan Chunde from Macedonia
 2. Second place photo contest winner Saúl Miranda Granados, Costa Rica
 3. Third place photo contest winner, Michael Benjamin Reyes (Philippines)

OTHER CONTEST ENTRIES:
 E. Enjoying a World Hemophilia Day event in India
 F. Young boy from Spain enjoying summer sun

WORLD HEMOPHILIA DAY LANDMARKS:
 A. Langevin Bridge in Calgary, Canada
 B. Leonard P. Zakim Bunker Hill Bridge in Boston, USA
 C. CN Tower in Toronto, Canada
 D. Niagara Falls, US and Canada

BELFAST



14TH INTERNATIONAL MUSCULOSKELETAL CONGRESS

**Belfast,
Northern Ireland
May 7-10, 2015**

Call for abstracts:
October 1, 2014

Deadline to submit abstracts:
March 6, 2015

Early registration:
December 12, 2014

Regular registration:
April 3, 2015



www.wfh.org/msk2015

In collaboration with:



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WFH launches simplified Chinese website

/Anna Maria di Giorgio, INTERIM WFH DIRECTOR COMMUNICATIONS AND MARKETING

In July, the WFH launched its localized website in Simplified Chinese, which received 619 page views in its first month. Already present online in our three official languages, the WFH is fortunate to have received positive feedback from a 2012 sponsorship request to enhance awareness in Simplified Chinese, Russian, Arabic and Brazilian Portuguese. For the WFH, creating these websites is about meeting the needs of our global community: China has more than 11,000 people with bleeding disorders; Russian-speaking countries, more than 14,000; Arabic-speaking countries, more than 17,000; and Brazil, more than 17,000.

“Creating awareness is the goal of any multilingual website,” said WFH communications manager Vanessa Herrick. “And being able to reach out to readers in as many languages as possible is a basic requirement for an international organization.”

The Simplified Chinese website is one of a number of localised sites that the WFH hopes to create over the coming months.

“In this first phase,” said Herrick, “we have translated basic informational pages and provided access to available publications in Simplified Chinese. By closely monitoring usage, we hope to get a sense of what is important to our readers in China so that we can improve the site over time.”

Guidelines now available in Arabic

Initially published in English, the WFH has been working to translate the 2nd edition of the guidelines into many different languages so that members of the bleeding disorders community around the world may benefit. In early August, an Arabic translation joined those in Chinese, French, Russian, and Spanish.

Hemophilia is a rare disorder that is complex to diagnose and manage. The *Guidelines for the Management of Hemophilia* aims to provide practical, evidence-based guidance to health care providers, government authorities and patient organizations seeking to initiate and maintain hemophilia care programs. It is the goal of the WFH that these guidelines encourage proper practice harmonization around the world and, where

recommendations lack adequate evidence, stimulate appropriate studies.

The WFH guidelines have been endorsed by the International Society for Thrombosis and Haemostasis and are available on the US National Guideline Clearinghouse website, as well as for purchase or download at wfh.org.



EMPOWERING FUTURE LEADERS IN THE GLOBAL BLEEDING DISORDERS COMMUNITY TO EFFECT POSITIVE CHANGE

Young Voices: Cultivating the next generation of leaders

/Fiona Robinson, WFH EDUCATIONAL MATERIALS MANAGER

Addressing an attentive audience at the WFH 2014 World Congress session on Leadership Development Strategies, former WFH president (2004–2012) Mark Skinner was emphatic in his call for the bleeding disorders community to plan for leadership succession. Many national and local patient organizations have been led by the same individuals for many years, and while they have been highly successful and motivated leaders, what happens when they retire?

“To develop into willing leaders, young people need to be given the opportunity to contribute their own ideas and develop their own leadership style.”

Young Voices is a series of online articles that is designed to help identify, mobilize and empower future leaders in the global bleeding disorders community to effect positive change.

The future strength of the WFH and of its national member organizations lies in its commitment to inspiring leaders who can work every day towards advancing the common vision of Treatment for All. The problem for many patient organizations is that they struggle to engage young adults within their communities and there is a need to inspire more active participation. The Young Voices series of articles is an attempt to bridge the gap and get youth involved.

By providing youth with the opportunities to get involved and to lead, the WFH is demonstrating confidence in their abilities, interest in their opinions, and fosters deeper commitment, and open communication.

New articles addressing the interests of young leaders will continue to be published every two months: www.wfh.org/youngvoices

CLOSE THE GAP

Campaign 2012-2014

75%

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

WHAT WILL IT TAKE TO CLOSE THE GAP?



He has a bleeding disorder.



So does he.



www.wfh.org/closethegap



Give to the Close the Gap Campaign: Your support will change lives

I am very pleased to be back as Fund and Resource Development chair at the World Federation of Hemophilia (WFH). It has been a true privilege to see the entire bleeding disorders community support the Close the Gap Campaign. The campaign was launched to help fund our next decade of development programs—and we still need to raise \$250,000 by the end of 2014 to reach our goal.

/Deon York, WFH FUND AND RESOURCE DEVELOPMENT CHAIR

Help us to reach our goal and to reach those around the world where the gap in care is greatest. Visit www.wfh.org and read the enclosed campaign bulletin to learn more about our cause and how the work you support transforms lives.

Your gift will

- train health care professionals to diagnose and treat people with bleeding disorders
- teach patients and families how to ease the suffering and pain of a bleed and of swollen joints
- deliver life-saving treatment to those in urgent need

And remember, the Patron's challenge also continues on until the end of 2014. That means however you decide to give your gift to the WFH will be tripled!

- Your gift of \$50 + \$100 from the Patron = \$150 to provide more training
- Your gift of \$500 + \$1,000 from the Patron = \$360 to send Humanitarian Aid to those who need it most



From Left to right, Frank Schnabel III, Deon York, and Frank Schnabel Jr.

THERE MANY DIFFERENT WAYS TO GIVE AND SHOW YOUR SUPPORT:

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

Monthly giving

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

\$5 per month x 12 = \$60
\$15 per month x 12 = \$180

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

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

Matching gifts

You can double the value of your gift without any further cost. Many employers match donations made by employees to eligible

non-profit organizations. Ask your human resources or public relations department if your employer has a matching gift program. Contact us at wfh@wfh.org to find out more.



GLOBALFEAST

Global Feast

You can use your wfh.org username and password to create your own fundraising and event page. Register at www.globalfeast.org and reach out to your entire social networking community to raise funds in your own way and raise awareness on behalf of the WFH.

CLOSETHEGAP
 Campaign 2012-2014

Building a network of specialized health care professionals

At the WFH 2014 World Congress a host of activities were organized to celebrate the success of the IHTC Fellowship Program. Since its inception in 1970, the Program has been instrumental in training medical professionals in developing countries in the diagnosis and treatment of hemophilia and other inherited bleeding disorders.



Left to right, WFH president Alain Weill, Dr. Santiago Bonanad, IHTC Director in Valencia (Spain), former WFH CEO John Bournas, and Dr. Hansjoerg Duerr, Vice President, Strategic Marketing Hematology, Bayer HealthCare

/Stephanie Pineda, WFH PROGRAM OFFICER IHTC AND IEQAS

At the Internet hub in the Melbourne Convention and Exhibition Centre, a few alumni as well as Dr. Margareth Ozelo, the IHTC director at Hemocentro Unicamp in Brazil, gave presentations on their experiences in the Program. Past fellows such as Nongnuch Sirachainan, a pediatrician from Thailand, as well as Sulochana B., a nurse from India spoke about their training, what they had learned, and how it has shaped their career.

Two of the IHTC directors who retired this year were recognized for their contribution to the program: Dr. Jose Aznar from the Hospital Universitario La Fe in Valencia, Spain as well as Dr. Roshida Hassan from

the National Blood Centre in Kuala Lumpur, Malaysia. Designated in 1997 and 1998, both IHTCs have provided support and training to many medical professionals around the world: hematologists, physiotherapists, nurses, orthopedic surgeons, laboratory scientist, and others.

At a dedication ceremony held on May 12, Dr. Santiago Bonanad, who is the current IHTC director in Valencia, and Dr. Faraizah Abdul Karim, the IHTC coordinator in Kuala Lumpur, accepted the plaques on behalf of Drs. Aznar and Hassan who could not attend Congress.

In addition to these events, the IHTC breakfast symposium took place on May 13. The goal of the symposium was to allow IHTC alumni

to network with other fellows and IHTC staff, share their experiences with one another, as well as reconnect with their former trainers. The event was well attended and featured presentations from Professor Mike Makris, the IHTC committee chair, and Dr. Huyen Tran, the IHTC director in Melbourne.

In order to strengthen the IHTC alumni network, the IHTC Fellowship Alumni newsletter was launched this year. The newsletter included statistics about the program, a report on the last IHTC breakfast symposium that took place in Amsterdam in 2013 and other relevant stories.

The IHTC Fellowship program is funded solely by Bayer.

Global Alliance for Progress highlights from Congress

/Antonio Jose Almeida, WFH PROGRAMS DIRECTOR

At the WFH 2014 World Congress in Melbourne the Global Alliance for Progress (GAP) Program kept to its mandate to greatly increase the diagnosis and treatment of people with hemophilia, and other bleeding disorders by acknowledging countries that have successfully completed their tenure in the program and also by welcoming new corporate partners.

The WFH announced at Congress three new corporate partners whose second decade GAP sponsorships contribute to the Close the Gap Campaign corporate goal of \$3.5 million: SOBI and Novo Nordisk who joined as Collaborating Partners and Kedrion joined as Friends.

As the GAP program aims to close the gap in treatment between developed and developing countries in three key areas: (1) the number of people born with hemophilia and those who reach adulthood; (2) the estimated and actual number of identified patients with bleeding disorders; and (3) the need versus the availability of treatment products. The WFH celebrated the successes of four countries that have made progress in these key areas at a special GAP event.

WFH president Alain Weill presented plaques to three Chinese delegates for their continued commitment to the GAP Program. When China first signed onto the program it had 2,600 people with hemophilia registered as patients compared to 11,108 in 2012. China has also expanded from six HTCs to 31, created more patient groups throughout the

country, created annual workshops for training and a whole host of other achievements that make China a stand out example of the success possible with the GAP Program.

Weill also presented plaques to Lebanon for its achievements that include the development of national treatment guidelines and increased training in the country. Tunisia also received recognition for its achievements in the creation of a national hemophilia registry and conducting awareness campaigns; and Belarus (who could not attend the reception) for its success in increasing the supply of CFCs and ensuring that a majority of people with severe hemophilia can now get home treatment.

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



Congress opens the door to talk about sexuality

The subject of sexuality might make some people uncomfortable yet it is a subject that is important to us all. For the bleeding disorders community, it is something that must be talked about in an open and straight forward manner. For many people though this is easier said than done.



Psychologist Frederica Cassis

/ Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

At the WFH 2014 World Congress, the subject of sexuality and bleeding disorders was open for discussion during several sessions and poster presentations. Ed Kuebler and Declan Noone spoke during their session titled, *Sexuality and Risk Reduction*, Greig Blamey and Alfonso Iorio presented their free paper on *Investigating attitudes and practices of Canadian physiotherapists on sexual health: A comparison to the HERO dataset*; an entire session was devoted to the subject of *Embracing Women's Sexuality* with Claire McLintock, Jill Smith, Lisa Thomas all speaking on a variety of topics around women and sex, and several posters were displayed. (*Addressing the sexual wellbeing needs of adolescents with hemophilia; Sex life and self-*

esteem in adults with hemophilia; and Love, sexuality and communication in hemophilia: A psychosocial and patient perspective book developed for adolescents, adults, and carriers.) These presentations and discussions were an important step in addressing a relevant issue for everyone in the bleeding disorders community.

For psychologist Frederica Cassis, WFH psychosocial committee member and long-time WFH contributor, sexuality is not only about the act of sex, it is about well-being, whether you are single or in a relationship, celibate or sexually active, a parent or without children. To be desired, cherished and loved is universal to the human experience and these feelings are no different for the young and not so young living with bleeding disorders. For Cassis it is vital to begin having this discussion with young people with bleeding disorders as soon as possible to remove the stigma attached to sex, because not talking about it with young people can lead to a whole host of issues for the one with the bleeding disorder and for their partners.

One of the most common feelings expressed by people with bleeding disorders when it comes to sexual intimacy is insecurity; insecurity about one's physical appearance, insecurity about bleeds, and a general insecurity about the act of sex. This rings true in both men and women with bleeding disorders. Issues that can also affect wellbeing are brought about by limitations in movement due to fatigue,

chronic pain, side effects from medications, as well as a lack of confidence in their appearance due to joint damage and the potential for a painful bleed. These may lead to a lack of desire and depression. These are things that go through the mind of every single person with bleeding disorders at some point in their lives but the hope is that through open discussion and education, the insecurities can (slowly) be cleared away.

These concerns people have are real and they need to be addressed so people have the tools to face their problems. Ignorance breeds fear, and not having proper information and counselling can lead people to feel isolated and alone. Psychologists like Cassis suggest that people with bleeding disorders should talk to a professional as early as possible to obtain information but also learn communication skills that would help improve the quality of relationships.

"Being able to mention these issues and others in a setting, either through counselling, with a parent, or with a doctor, can be very helpful because the person could learn to cope with these difficulties," said Cassis. "A lot of people's concerns are about how to communicate these issues related to health to a partner and still give off a positive self-image to others."

The goal of having sessions and discussions like those at the recent Congress in Melbourne is to open up the discussion and break the

continues on page 30



Middle Eastern and African NMOs gather in Dubai for advocacy training

From August 29 to August 31, national member organizations (NMOs) from across the Middle East and Africa gathered in Dubai, UAE, for an Advocacy in Action workshop that focused on building awareness and government support for the bleeding disorders communities in their respective countries.

/Marianna Balakhnina, WFH ADVOCACY IN ACTION PROGRAM COORDINATOR

Sixteen NMOs participated in the three-day event that covered topics ranging from building relationships with key stakeholders and using media for advocacy to sharing lessons learnt from advocacy experiences of each country. This was critical training for these organizations given the multiple challenges they face, including influencing and getting support from government and other key institutions, as well as developing strong ties with medical leaders and learning how to use these relationships to advance advocacy strategies.

During the meeting, there was a mix of lectures, group exercises and role-playing activities to give participants the tools to better advocate for proper care in their countries. Arafat Awajan, vice-president of the Jordan Thalassemia and Hemophilia Society, was in attendance to speak of his NMO's experience of developing and maintaining government support. Magdy El-Ekiaby, MD, board member of the Egyptian Society of Hemophilia, offered advice on how to achieve better collaboration between medical and lay communities to advocate for better care.

The goal of the Advocacy in Action workshops is to provide NMOs with targeted strategies and tools for dealing

with challenges in obtaining and securing government support and to improve the diagnosis and treatment of bleeding disorders. Strained budgets, lack of interest or will, and difficulty in dealing with bureaucracies are all common issues that many of the NMOs know all too well. The goal of the workshops was to provide a place where the NMOs can acquire knowledge and share their success stories and challenges with other organizations in order to achieve a stronger voice for the bleeding disorders community that is needed in many countries around the world.

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

Twenty years later: Blood safety in America and the Ricky Ray Act

/Vanessa Herrick, WFH COMMUNICATIONS MANAGER

This past September, the National Hemophilia Federation (NHF) had their annual meeting with a special plenary session called *Celebrating 20 Years of Blood Safety and the Ricky Ray Act*. It marked the anniversary of the beginning of the extraordinary advocacy movement in the United States that resulted in the Ricky Ray Relief Act. The act passed in 1997 and addressed the need for greater blood safety and blood product safety in the US. It also mandated a compensation program for individuals infected with HIV from blood products.

Though the act passed in 1997, 1994 remains significant as it was the year that several members of the US Congress brought their concerns about the impact of HIV/AIDS on men and children with hemophilia to then Secretary of Health and Human Services Donna Shalala.

Shalala contacted the Institute of Medicine (IOM) for assistance and requested a study be done. The result was the landmark IOM report, *HIV and the Blood Supply*, which was a critical turning point in the battle for blood safety. A link to the plenary can be found on the NHF's website at www.hemophilia.org and on the NHF's YouTube channel.

Moldova marks its fourth year of GAP Program with eightfold increase in CFC supply

In the four years since joining the GAP Program, the Moldova Hemophilia Society (MHS) has made significant steps forward in advancing hemophilia care within the country. One of the main achievements is a recent significant increase in the purchase of life-saving clotting factor concentrates (CFCs).

/Salome Mekhuzla, WFH REGIONAL PROGRAM MANAGER, EUROPE

Earlier this year, the Ministry of Health of the Republic of Moldova carried out the 2014 year tender and 1.2 IUs/per capita of FVIII and FIX were purchased; this means that the initial GAP target of 0.65 IUs/per capita was doubled. The amount of CFCs purchased in 2014 exceeds the CFC supply in the first year of GAP program (2011) by about eight times.

A major step forward in the treatment of hemophilia B in Moldova came in 2013 when the Ministry of Health purchased FIX for the first time.

Another important achievement of the GAP Program is enhancing the medical expertise by providing both in-country and international training opportunities for members of the hemophilia care team at the pediatric and adult hemophilia training centres (HTC) in Chisinau. Both HTCs also have internationally trained physiotherapists and in 2013 the

WFH purchased physiotherapy equipment for both centres so that they can now offer better physiotherapy services to patients with bleeding disorders.

In March 2014, the WFH and MHS organized a one-day conference on hemophilia treatment with Dr. Jerzy Windyga from Poland leading several interesting discussions. Around 40

participants took part in the conference including medical professionals, patients with hemophilia and their family members.

The Moldovan Hemophilia Society has also created a computerized national patient registry, which will be managed by the Chisinau HTC.



A story of survival

continued from page 9

The impact was extraordinary. With a magnitude of M_w 9.1–9.3, it was the third largest earthquake ever recorded on a seismograph. While the earthquake itself was catastrophic, it triggered what is now remembered as one of the deadliest natural disasters in recorded history. The 2004 Indian Ocean tsunami destroyed boats, homes, and swept away entire communities in seconds with waves of up to 30 metres (100 feet) high. Fourteen countries were hit, almost 230,000 people were killed and the largest humanitarian aid effort in human history ensued.

But for Overstreet, her only focus was Chetan. The impact of the tsunami was felt across India, and almost immediately communications systems went down. Chetan was not in a region directly hit by the waves but Overstreet knew her son was in the hospital with a critical brain bleed at the time of the tsunami and didn't know anything else. "I had no idea what was going on. I was sick to my stomach."

When asked what she felt when she woke up to the news of the devastation in the region

she remembers the frustration she felt, "I almost just got on a plane. But I had no idea what my legal status was at that point since the adoption was not complete. And I knew aid agencies from around the world were all heading to the region so I was not sure I would even get a flight."

A NEW LIFE

She waited for a week to hear an update on Chetan. Finally, the phone rang with the news that he was ok and was back at the orphanage where they were preparing all of his medical records for her. Overstreet secured two doses of factor from her local Hemophilia Treatment Centre and left with her husband to bring Chetan home.

The story of getting Chetan home to the United States is one that features the help of many people that Overstreet has not forgotten, the doctors and nurses at the hospital, the embassy worker who bent the rules to ensure that she and Chetan could get out of the country the same day, the airport doctor who granted Chetan permission to fly knowing that he was in danger but needed to get to a

premium care facility as soon as possible and every hour counted.

The story thankfully ends well. Chetan made a complete recovery upon arrival and has had no long-term physical damage as a result of his childhood injuries or bleeds.

"The doctors were stunned to see there was no damage. When they saw his knees when he arrived in America they were sure we were looking at physical therapy, and then within six weeks he had normal mobility," she says.

Chetan has no memory of being in India; he has no interest returning and has not talked about finding his father. He is good in school and has expressed a desire to be a hematologist. "He knows it will be a lot of work but he wants to show other boys that they can live a normal life," Overstreet says.

Overstreet still thinks of Chetan's father. "We've tried to go back and find him, we have been unsuccessful. The one thing I've wanted to do for ten years was tell this man that this child has a family, that he is thriving, that he is loved." But there is hope she explains. "The law in India is that at the age of 18, Chetan can go to court and demand that the files be opened."



The WFH 2014 World Congress in Melbourne, Australia was one of our most successful yet. Over 4,000 participants from 128 countries around the world gathered down under to share knowledge and ideas all with the goal of improving the treatment and care for people with inherited bleeding disorders. From May 11 to May 15, there were a host of sessions, talks and events that kept our attendees engaged and hopefully entertained. Here are just a few snapshots of what went on at the WFH 2014 World Congress.







Front row (left to right) Pamela Wilton, Eric Stolte, Alain Weill, John Bournas, Marijke van den Berg. Top row (Left to Right) Declan Noone, David Silva, Magdy El Ekiaby, Flora Peyvandi, Jan Willem Andre de la Porte, Cesar Garrido, Jerzy Windyga. (Keith Hoots and Deon York not pictured)

Thank you outgoing members and welcome new board members

At the General Assembly of the WFH 2014 World Congress in Melbourne, Australia, our national member organizations voted in new members to the newly named WFH Board of Directors (formerly the WFH executive committee).

As new members begin their time with the WFH we would like to extend a gracious thank you to the outgoing members of the board for their time and considerable efforts to the WFH vision of Treatment for All.

To the new members, on behalf of the WFH and our global community, we extend a warm welcome and look forward to each of your unique talents all focusing on one goal; better treatment and care for people with an inherited bleeding disorder.

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Zealand

Keith Hoots, MD
MEDICAL MEMBER/USA

David Silva Gomez
LAY MEMBER/Spain

Pamela Wilton
LAY MEMBER/Canada

Calendar of events

Congress on Controversies in Thrombosis and Hemostasis (CiTH)

October 30–November 1, 2014
Berlin, Germany
Tel.: +972 73 706 6950
Fax: +972 3 725 6266
eMail: cith@congressmed.com
www.congressmed.com/cith

World AIDS Day

December 1, 2014
United Nations
www.un.org/en/events/aidsday

ASH Annual Meeting

December 6–9, 2014
San Francisco, U.S.A.
American Society of Hematology
Tel.: +1-202-776-0544
Fax.: +1-202-776-0545
eMail: meetings@hematology.org
www.hematology.org

8th Annual Congress of EAHAD

February 11–13, 2015
Helsinki, Finland
Tel.: +41 22 33 99 579
Fax.: +41 22 33 99 631
eMail: eahad2015@mci-group.com
www.eahad2015.com

59th Annual Meeting of the Society of Thrombosis and Hemostasis Research

February 24–27, 2015
Düsseldorf, Germany
Tel.: +49 (0)30 20 45 90
Fax: +49 (0)30 20 45 950
eMail: gth2015@mci-group.com
www.gth2015.org

International Plasma Protein Congress 2015

March 10–11, 2015
Rome, Italy
Tel.: +32-0-2-705-5811
Fax.: +32-0-2-705-5820
eMail: alexa@pptaglobal.org
www.ippc.net; www.pptaglobal.org

World Hemophilia Day 2015

April 17, 2015
World Federation of Hemophilia
Tel.: + 1-514-875-7944
eMail: vherrick@wfh.org
www.wfh.org/whd

14th WFH Musculoskeletal Congress

May 7–10, 2015
Belfast, Northern Ireland
World Federation of Hemophilia
Tel.: + 1-514-875-7944
www.wfh.org/whd

Building a community through music: HAPLOS Ukulele Club

When searching for an activity to bring people in the bleeding disorders community closer together, the Hemophilia Association of the Philippines for Love (HAPLOS) chairman John Sarmenta knew of no better way than through music.

/Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

“HAPLOS was looking for a youth program that would engage the youth and develop their talents, and at the same time would be a productive outlet for their expression,” Sarmenta said.

The only question left was which instrument suited their needs best. “My parents and family had always been musically-oriented. We bought a ukulele in 2011 and soon realized how accessible and appealing it was, and started bringing one for entertainment during community gatherings,” said Sarmenta who then brought up the idea with his colleagues and in September 2013, the first HAPLOS Ukulele Club lessons got underway.

The ukulele was the perfect instrument for the program in that it is popular, affordable, allows for an expert to display technical skill while also being easy for beginners to pick, very portable, and because of its size and relatively low cost when compared to a guitar or perhaps a violin.

COMING TOGETHER

For the people in the bleeding disorders community, having a place where they can meet other people like them and share in a group activity is essential but the program does have other benefits.

“Something as simple as a ukulele club can be many things. Music in itself is gaining popularity in psychological interventions, especially in dealing with children, noted for building rapport, relieving stress, allowing for safe and productive self-expression, which is vital to mental health. In between actual lessons, club meetings are opportunities for members and their accompanying families to form new bonds and strengthen relationships with other members,” said Sarmenta.

For Sarmenta, music has a way of bringing people together like nothing else and in addition to all the benefits for the individual, the club has given HAPLOS a way to raise funding for its programs through concerts



Some members of the HAPLOS Ukulele Club taking a break.

and builds a sense of pride with the younger members, hopefully leading them to inspire others and become possible future leaders and champions of advocacy.

The program is currently funded by private donations, but to kick start the project in its first year the cost of the ukuleles was shouldered by the members of the board. This is the club's only major expense as the venue and the lessons are donated and run on volunteer time.

REACHING OUT

The reaction from those involved in the club has been incredibly positive. While the club was first conceived as an activity for the younger members of the community, some of the older members have enrolled and love telling and impressing their friends with their new abilities. For the young children with bleeding disorders the club has been a resounding success.

“Young children who have attended several sessions have visibly improved confidence and sociability with other members. Some children who were shy and also others who were initially hard to get along with, can now be found sitting at the same tables with their friends from the ukulele club during HAPLOS gatherings,” said Sarmenta. “Parents say that their children share the day's lesson with them and some children are even bringing their ukuleles to school. Overall response has been very positive.”

Some of the most popular songs played by the club are *Rainbow Connection* from the Muppets, *Let it Go* from the soundtrack to the Disney movie *Frozen*, *I'm Yours* by Jason Mraz and many popular Filipino children songs. The Haplos Ukulele Club has officially played two concerts. Their biggest show was during the HAPLOS Christmas party where they played in front of a crowd of over a hundred people.



Global NMO training brings members together

From May 8-10, the WFH hosted its national member organization meeting in picturesque Creswick, Australia where 101 delegates from across the world came together to discuss issues facing their organizations and share lessons learned since they had last met.

/ Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

Daily plenary sessions focused on important issues such as NMO sharing best practices, an update from the WFH and a very popular session on women with bleeding disorders. Sonia Adolf, MD, Arlette Ruiz-Saez, MD, Alison Street, MD, and Pamela Wilton shared professional and personal stories about the status of women in the bleeding disorder community and what progress has been made, as well as what progress needs to be made. This session was followed by Marijke van den Berg, MD, Brian O'Mahony, and Alok Srivastava, MD, speaking on the roles NMOs and people with hemophilia play in research, with some insight into the new WFH Research Program.

The plenary sessions were simultaneously translated into four languages: English, French, Spanish and Russian, and allowed for experts from across the world to overcome language barriers and impart important information to the group.

Daily workshops were also held and were designed to assist NMOs in dealing with their professional commitments as well as improving their service to patients. A series of experts reviewed the role that data plays in the economics of bleeding disorder care and how NMOs can use data as a tool in advocating for their patients. Richa Mohan reviewed what kind of psycho-social support NMOs can provide to patients and families and how to empower patients to take an active role in their psychosocial care. Brian O'Mahony and Cesar Garrido presented in English and Spanish on the benefits and possible consequences of accepting industry funding and how to maintain control of the agenda.

There was also a workshop facilitated by Suzanne O'Callaghan on the ways to identify, train and sustain potential youth leaders in an NMO and what other organizations have experienced in their youth leadership programs.

Sexuality

continued from page 23

stigma, starting with those on the front lines of care having the right information who in turn pass it down to the patient in all corners of the globe.

"It is not about telling people how to have sex, but about giving the most useful information to someone with a specific issue, so he/she can have the right mindset (and information) to fully enjoy the heat of the moment," said Cassis.

The good news for the community, as the data shows from the HERO (Haemophilia Experiences, Results and Opportunities) study, people with hemophilia in sexual relationships have an overall high rating of satisfaction in their sex lives and that with a little knowledge they don't have to feel like they are not normal.

- from 675 PWH who answered in the HERO quantitative study;
- 384 PWH were in relationships;
- of these, 324 (85%) answered questions regarding sexuality and intimacy;
- 78% (236 of 303) responded they were extremely/moderately satisfied with the overall quality of their sex life.

Frederica Cassis, Irene Fuchs and Edward Kuebler have worked together to produce a booklet on the subject of sexuality and hemophilia that is currently only available in Spanish. English and Portuguese editions will soon be available. The booklet's name is *Amor, Sexo y Comunicación en hemofilia* or *Love, Sexuality and Communication in hemophilia*.

WFH 2016 Congress trip winner's act of generosity

At the WFH 2014 World Congress Frank Schnabel III selected lucky winner Peter Pustoslemsek for the 'Make Your Mark' draw to win a free trip to the WFH 2016 Congress in Orlando, USA.

As happy as Mr. Pustoslemsek was upon hearing the news, he graciously declined the free trip in favour of giving it to someone who he thought would benefit from the Congress. He was very pleased to offer the prize to Premroop Alva as a tribute to his late friend, and founder of the Hemophilia Federation (India), Ashok Verma – 2004 International Frank Schnabel Volunteer Award winner. Premroop happily accepted the generous offer and is looking forward to Congress in 2016. Premroop, a past WFH Youth fellow and current general secretary of the Indian Hemophilia Society - Bangalore Chapter, was recently profiled in the 2013 WFH Annual report, which is now available on the WFH website.

Thank You

In recognition of the organizations that have committed or contributed to the WFH's mission so far in 2014

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Jan Willem André de la Porte

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Prophylaxis section: Biogen Idec Hemophilia
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Advocacy in Action—Sharing best Practices Symposia/Reception: Baxter
Inga Marie Nilsson Award: Octapharma
Iraq Hemophilia Community Empowerment Initiative: Pfizer
National Bleeding Disorder Symposium: CSL Behring
Iraqi Physiotherapy & Nurses Training Workshops: Pfizer
Susan Skinner Memorial Fund: The Hemophilia Alliance
von Willebrand Disease Workshop: LFB

World Hemophilia Day

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

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340B Factor Program at Akron Children's
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Belgian Haemophilia Society*
Canadian Hemophilia Society*
Colorado Chapter of the National Hemophilia Foundation
CXG
Diagnostics Stago
Federacion de Hemofilia de la Republica Mexicana*
Fondazione Angelo Bianchi Bonomi
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Habataki Welfare Project (Japan)
Haemophilia Foundation of New Zealand*
Hemophilia Foundation of the Philippines for Love (HAPLOS)*
Hemophilia of Georgia
Hospital Infantil Pediátrico/Hospital Escuela (Honduras)
Irish Haemophilia Society*
National Hemophilia Foundation (U.S.A.)*
Opticom International Research AB
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Rocky Mountain Hemophilia and Bleeding Disorders Association
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Swedish Hemophilia Society (FBIS)*
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The Haemophilia Society (U.K.)*

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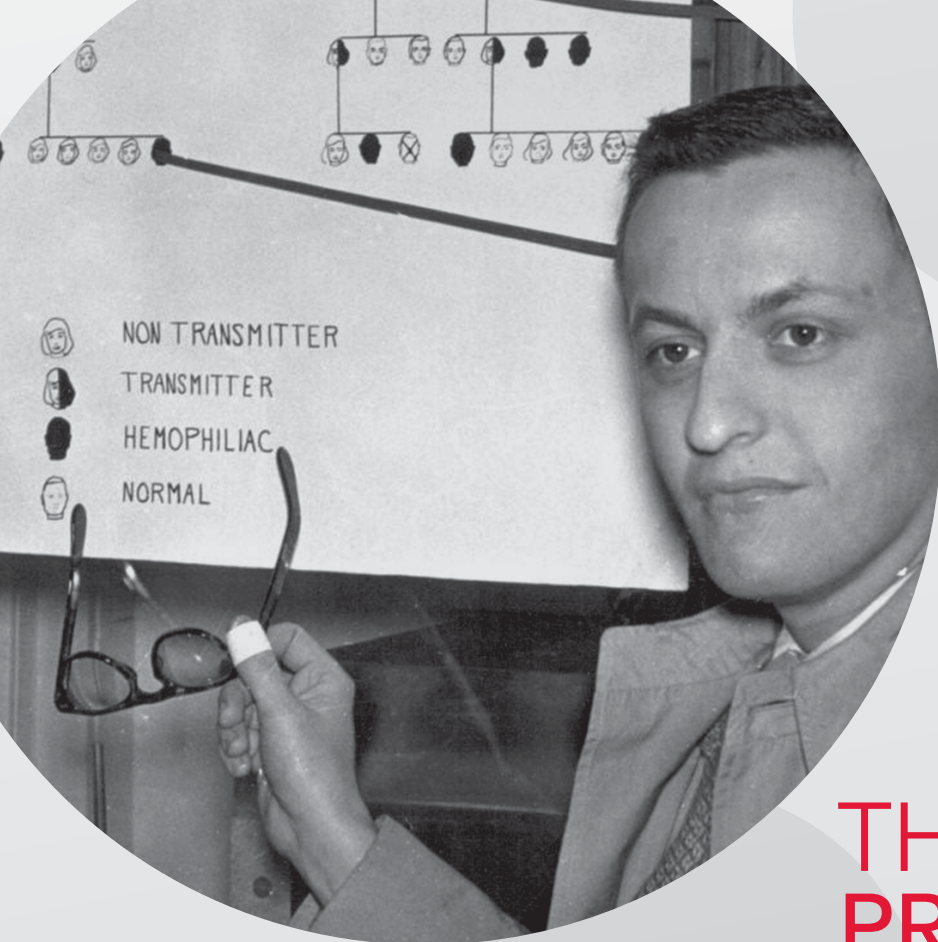
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HEMOPHILIA WORLD WOULD LIKE TO HEAR FROM YOU!

The activities of people living with hemophilia and other inherited bleeding disorders, and their organizations, are important to everyone in the global bleeding disorders community. We welcome stories, letters, and suggestions for articles. Please send them to:

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