

HEMOPHILIA WORLD

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www.wfh.org



Record Numbers Attend the Hemophilia 2010 World Congress in Argentina

Craig T. McEwen

WFH CONGRESS AND MEETINGS DIRECTOR

The XXIX International Congress of the World Federation of Hemophilia (WFH) was the most successful Hemophilia World Congress to date. Over 4300 participants from 106 countries attended the four day event, held in Buenos Aires, Argentina.

During the Congress, the WFH's Resource Centre focused on the theme of the "Many Faces of Bleeding Disorders", which reflects the wide and varied make up of our global community. Contemplating this theme, one participant from the Philippines said, "The many faces show the different adults and children, all smiling, but looking out for hope that there will be a better future for them. It's world-wide, not just a single culture. It shows that there are a lot of people and members of society involved."

The WFH's World Congress is the largest international scientific meeting place for the global bleeding disorders community. Renowned international treatment and research experts from around the world participated. This scientific meeting is held for all members of the bleeding disorders community and it is here that breakthroughs in this field are presented.

This Congress was organized by



LEFT: Maximiliano Guerra performs at the Opening Ceremony RIGHT: Delegate Shirin Ravanbod reading the Congress program



the WFH and hosted by the Fundación de la Hemofilia of Argentina. "As Latin Americans, we feel an immense pride in becoming a meeting point that encourages sharing new knowledge in hemophilia treatment," said Fundación president Carlos Safadi Márquez and Congress president Raul Perez Bianco in their welcoming letter.

ENJOYING THE LATIN SPIRIT

The Opening Ceremony began on the Saturday night with nearly 3000 participants enjoying the passionate Latin style and grace of the Argentinean ballet. Maximiliano Guerra and the Mercosur Ballet

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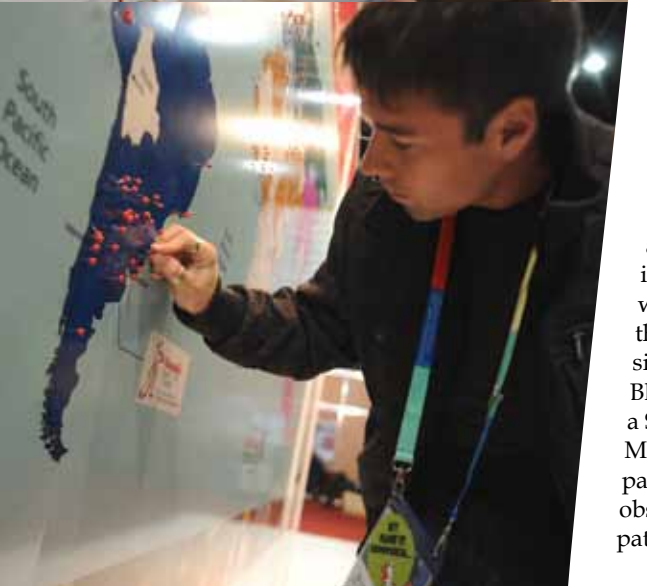
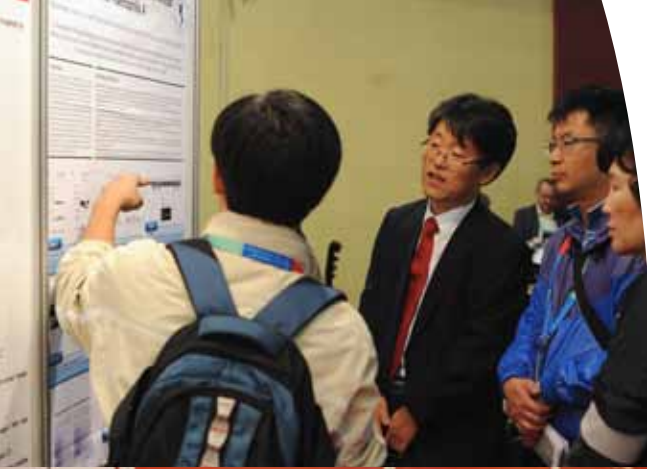
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WORLD FEDERATION OF
HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA
Treatment for All





2010 WORLD CONGRESS

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performed two stunning acts that concluded with the Tango, the traditional dance of Argentina.

On Monday night, Congress participants were treated to an evening of traditional Argentinean folklore and dance, as local artists entertained attendees during the Congress cultural event. More than a few people will return home more skilled at the Tango after receiving lessons during the event.

The XXIX International Congress of the World Federation of Hemophilia (WFH) was the most successful Hemophilia World Congress to date.

PRE-CONGRESS SESSIONS

Taking place on Saturday, July 10, 2010, these practical workshops addressed key issues in nursing, physiotherapy, orthopedics, psychosocial work, laboratory science, and gene therapy. In addition, there were sessions on topics such as Women with Bleeding Disorders and How to Publish a Scientific Paper. In the pre-congress Musculoskeletal-Orthopedic session, participants had the rare opportunity to observe two live surgical procedures on patients with hemophilia.

PHOTOS TOP TO BOTTOM: Poster Session; Selection of publications at the WFH Resource Centre; Delegate putting pin in map at WFH Resource Centre; Dancers entertain the crowds at the Cultural Event

THE LATEST INFORMATION ON BLEEDING DISORDERS

The Congress medical and multidisciplinary programs provided a rich diversity of presentations in the plenary and scientific sessions. These included basic scientific reviews, updates from clinical trials, commentaries on regulatory and training issues, and 'late-breaking news'. It was a very contemporary look at the state of knowledge of hemophilia and other bleeding disorders. There were a total of 786 abstracts presented at Congress this year.

When asked what was the most important reason for attending this Congress, one delegate from Brazil said, "I'm looking for new information about recent developments in the area, and looking forward to strengthening bonds and collaborations with other people."

Throughout the week the sessions were filled and there was a steady stream of traffic through the exhibition hall, and many of the delegates viewed the poster presentations.

Read more about both the medical program on page four and the multidisciplinary program on page six.

MAKING A WORLD OF DIFFERENCE AT CONGRESS

Delegates from around the world helped support the WFH by generously contributing donations at Congress. A record amount totaling over US\$10,000 was donated by over 350 delegates who participated in the WFH Make a World of Difference fundraising campaign. Learn more about this campaign and the other WFH Congress fundraising initiatives on page 11.

TREATMENT CENTRE AND PHYSIOTHERAPY CENTRE

During the pre-congress and congress period, 86 people from 44 countries used the services of the treatment centre, with a total of 240 visits. A total of 904,880 international units and 50 mcg of donated products were used. Read more about the treatment centre and the humanitarian aid donations on page eight ■



BONJOUR PARIS

The WFH 2012 World Congress will be held in Paris, France, from Sunday, July 8, to Thursday, July 12. During the 2012 Congress, the WFH will begin celebrations for its 50th Anniversary, which takes place in 2013.

WFH President Mark Skinner Opens Congress by Addressing the Underserved Populations in our Global Family

The Hemophilia 2010 World Congress of the World Federation of Hemophilia (WFH) opened with the WFH president's plenary, focusing on our global family. In particular, Mark Skinner addressed the needs of the underserved populations in the global bleeding disorders community.

"Women and men, young and old, and those in developing and developed countries are all important members of our global family, regardless of where they might live in the world," said Skinner. The WFH's mission to improve and sustain care "goes beyond hemophilia to incorporate advocacy and support for all people with inherited bleeding disorders."

Remarkable progress in diagnosis and care has been achieved in many areas to date, but much work remains to be carried out, particularly for women with bleeding disorders, patients and families in sub-Saharan Africa, and children and youth.

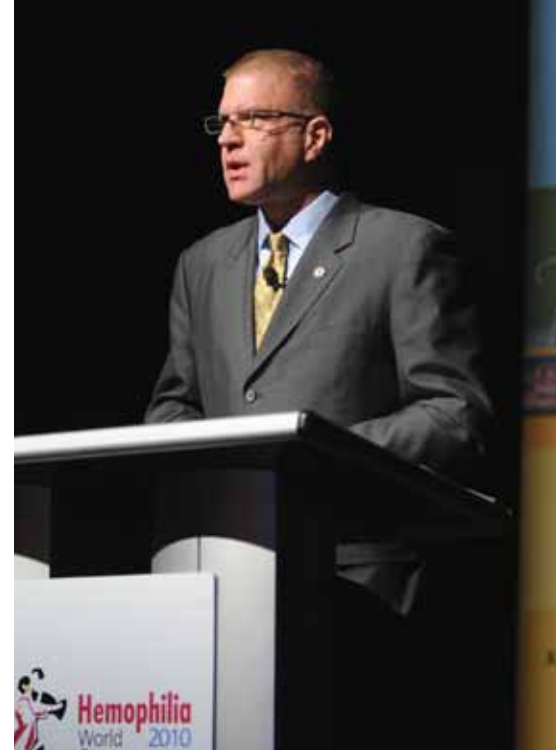
Women with bleeding disorders, including von Willebrand disease (VWD), rare factor deficiencies, inherited platelet disorders, and carriers of hemophilia, often have no idea that their symptoms are abnormal, even though they have a significant impact on quality of life. Lack of awareness among

caregivers often delays proper diagnosis and treatment when they do seek help.

In 2003, the U.S. Centers for Disease Control and Prevention found that women with VWD wait an average of 16 years from onset of symptoms to diagnosis. Furthermore, some estimates place the incidence of VWD as high as 1.3% of the global population. "The number of women reported with bleeding disorders is growing rapidly in some developed countries," said Skinner. "The next step is developing innovative tools and strategies that can be adapted globally to accelerate the identification and treatment of women with bleeding disorders."

With only 15 of 53 African countries as national member organizations, it is the most underrepresented regional area of the WFH member organizations. This year, the WFH welcomed Ethiopia, Ghana, and Tanzania as new members (along with Bolivia and Suriname). However, there is more to be done to improve diagnosis, training, and capacity-building, through three regional centres in sub-Saharan Africa – Kenya in the east, Senegal in the west, and South Africa in the south.

"Integral to the approach to achieving Treatment for All is building a core centre



WFH president Mark Skinner

of expertise within each African region to serve as a hub for further regional development, as well as regional role models," said Skinner. Regional training workshops and the WFH's twinning program, for example, maximize opportunities for practical learning and achieving sustainable care.

"An analysis of data collected since the introduction of the WFH Global Alliance for Progress (GAP) program in 2003 demonstrates improvement in the mortality of patients with hemophilia," said Skinner. "These improvements can be achieved even in countries with lower levels of economic development or limited access to clotting factor concentrates."

WFH programs have played an important role in improving care delivery. Education and psychosocial support of patients and families, better organization of care, and training of multidisciplinary health teams can reduce mortality, independent of the availability of clotting factor.

Securing youth involvement was also a key focus of the plenary. The WFH's recent steps to integrate youth into the work of the organization were described, as was the expansion of youth programs to ensure that a future generation is ready to assume the mantle of leadership.

While a lot has already been achieved, with this renewed focus, the WFH aims to continue striving for access to treatment for all people with inherited bleeding disorders, no matter where they live. ■

For Mark Skinner's paper "Building our global family – achieving treatment for all", visit www.wfhi.org.



Tanzania is welcomed as an accredited national member organization at the WFH General Assembly



LEFT: Adolfo Llinas speaking at the live surgery presentation RIGHT: Dr. Claude Negrier presenting at the Novel Therapies plenary session

Experts Share Medical Breakthroughs, Challenges at Hemophilia 2010

Alison Street, MD

WFH VICE-PRESIDENT MEDICAL CONGRESS
MEDICAL SCIENTIFIC COMMITTEE CO-CHAIR

Renowned leaders in bleeding disorders research and care converged in Buenos Aires to discuss state of the art themes. Here are some highlights from this year's outstanding contributions.

AGEING POPULATIONS

The bleeding disorders community is now facing similar challenges to the general population, as improved treatments and longer life spans bring problems of ageing to the forefront of hemophilia care. Dr. Gerry Dolan (U.K.) spoke of new health issues people with hemophilia face as they age. Heart disease, cancer, kidney failure, and osteoporosis are all increasing, with 77% of seniors over 65 having two or more chronic conditions. There is very little experience managing multiple medical conditions in older people with hemophilia. Previous data on cardiovascular disease in people with hemophilia has been mixed, but it now seems that hemophilia is not protective against atherosclerosis. An ageing population with bleeding disorders will use substantially more clotting factor concentrates, as well as experience a gradual increase in inhibitors. More data need to be collected on the magnitude and optimum treatment of age-related disorders to assist advocacy for adequate services.

PROPHYLAXIS

Dr. Victor Blanchette (Canada) reviewed data on the well-documented benefits of primary prophylaxis, and the more limited data on secondary prophylaxis, particularly in adolescents and adults. The optimal regimen for initiating and escalating primary prophylaxis is still undetermined, and the role it plays in individuals with severe von Willebrand disease as well as other rare bleeding disorders must be investigated.

Cost-benefit analysis for treatments is a critical issue. Dr. Alok Srivastava (India) proposed the introduction of prophylaxis programs in developing countries even as soon as 1 to 2 international units of clotting factor concentrates per capita is available. He advised that all programs should include careful measurements of musculoskeletal outcomes.

JOINT IMAGING

Dr. Andrea Doria (Canada) spoke of magnetic resonance (MRI) and ultrasound imaging techniques which detect earlier changes in hemophilic joints than X-rays. Already, MRI delivers critical information on sub-clinical bleeds not available through conventional radiography or clinical examination. Standardized protocols for data acquisition and interpretation of images are required.

LIVE MUSCULOSKELETAL SURGERY

During a pre-congress session, two surgical procedures performed by Dr. Horacio

Caviglia (Argentina) were broadcast live from Hospital General de Agudos Juan A. Fernández. The first was a revision of a hip fracture in a 64-year-old man with severe hemophilia A. The second patient, a 16-year-old with severe hemophilia B and synovitis of his knee, had the genicular arteries embolized under imaging control. This required comparatively small amounts of factor replacement and is an exciting alternative to arthroscopic synovectomy.

WOMEN AND BLEEDING DISORDERS

Although rarely affected by hemophilia, women are equally likely as men to have other bleeding disorders. Dr. Andra James (U.S.A.) stressed the importance of combining the expertise of hematologists and obstetricians/gynecologists to ensure optimal management. She reviewed existing guidelines and standard practices in managing menorrhagia and other gynecological bleedings, pregnancy, and childbirth. These important issues, as well as prenatal diagnosis and the management of psychological impact and quality of life, were further explored in a pre-Congress session chaired by Dr. Rezan Kadir (U.K.) and Flora Peyvandi (Italy).

NEW TREATMENTS

People with hemophilia may soon require infusions only once a week or less, due to a cluster of novel therapies with the possibility of "impressive extension in half-lives,"



People with hemophilia may soon require infusions only once a week or less, due to a cluster of novel therapies with the possibility of “impressive extension in half-lives,”

Dr. Claude Negrier reported.

Dr. Claude Negrier (France) reported. This should also bring improved quality of life and reduced treatment costs. Several strategies have been used to extend the half-life of treatment products, including site-specific pegylation of the factor VIII and IX molecules. The safety and efficacy of all novel products will need to be carefully assessed through well-designed international clinical trials. Determining immunogenicity is the major question that will arise. Dr. David Lillicrap (Canada) described animal models that could lead to better pre-clinical methods to predict inhibitor formation.

GENE THERAPY

Much-anticipated breakthroughs in gene transfer therapy are still taking shape, including a number of new, non-traditional approaches. Dr. Paul Monahan (U.S.A.) presented animal research supporting the potential of treating with clotting factor concentrates directly into target joints, while a new understanding of co-localized von Willebrand factor and factor VIII suggests feasibility in using platelet-directed expression of factor VIII as a gene therapy treatment for hemophilia A, according to Dr. Robert Montgomery (U.S.A.). Dr. Margaret Ozelo (Brazil) described *ex vivo* delivery of therapeutic transgenes using modified blood outgrowth endothelial cells.

INHIBITORS

Dr. Donna DiMichele (U.S.A.) presented preliminary final results from the recently terminated International Prospective Randomized Immune Tolerance Study, which showed some clinically significant differences between high- and low-dose regimens. Patients on low-dose took twice the time to record both a negative inhibitor titer and then to achieve tolerance. Dr. Charles Hay (U.K.), presenting safety data

from the same study, showed no difference in catheter infections, but significant increase in bleeding in the low-dose group, particularly before achieving a negative titer.

In her Arosenius lecture, Dr. Kathy High (U.S.A.) explained how gene therapy can both reduce the risk of inhibitor formation and treat its occurrence via induction of clotting factor-specific regulatory T-cells that lead to tolerance of the factor IX protein. Her colleague Dr. Valder Arruda (U.S.A.) described a gene therapy vector to effect continuous delivery of factor VIII protein, thus effectively preventing inhibitor formation.

Finally, Dr. Alessandro Gringeri (Italy) outlined the progress of the SIPPET (Survey of Inhibitors in Plasma- Product Exposed Toddlers) study, comparing the incidence of inhibitors in patients treated with plasma-derived and recombinant products.

PRODUCT SAFETY

Dr. James Ironside (U.K.) reported on a probable case of asymptomatic transmission of variant Creutzfeldt-Jakob disease (vCJD) in a 70-year-old with hemophilia. This patient received significant amounts of factor concentrates, the most likely source of prion transmission. If levels of infection were high in these products, he said we would expect to have seen many more hemophilia patients with symptomatic vCJD.

Parvovirus B-19 continues to frustrate manufacturers' efforts to eliminate it from both recombinant and plasma-derived products. Dr. Jeanne Ann Jordan (U.S.A.) explained that it is highly resistant to current inactivation methods, with products from pooled donations appearing to have the highest rates of infection. Nanoexchange and chromatographic techniques are in development to further reduce risk.

LABORATORY DIAGNOSIS AND MONITORING

At a pre-congress workshop, Dr. Andreas Hillarp (Sweden) discussed the selection, use, and limitations of prothrombin time and activated partial thromboplastin time assays for detection of bleeding disorders. Dr. Ampaiwan Chuansumrit (Thailand) demonstrated her centre's bedside kit for diagnosing hemophilia A and B, and Dr. Angus

McCraw (U.K.) described the detection of inhibitors in acquired hemophilia patients.

In another session, Dr. Steve Kitchen (U.K.) discussed performing both one- and two-stage assays in all diagnoses of mild hemophilia A, since the condition is not excluded by finding a normal factor VIII:C level by one-stage assay. Dr. Claude Negrier and Dr. Yesim Dargaud (France) discussed methods of classifying the severity of bleeding disorders. Factor levels from clotting-based or chromogenic assays have variable correlation with clinical phenotype. Global coagulation assays like the thrombin generation test can show better correlation with bleeding tendency, but are not used to classify severity or screen for bleeding risk.

Dr. Cathy Hayward (Canada) highlighted the need for standardized lab testing to diagnose platelet function disorders. Without standardization, platelet disorders are both under- and over-diagnosed, leading to inconsistent treatment.

INFECTIOUS COMPLICATIONS

HIV and hepatitis C (HCV) infections continue to be of great concern to people living with bleeding disorders. Dr. Margaret Ragni (U.S.A.) noted that HCV infection remains the leading cause of end-stage liver disease. In those with HIV co-infection, treatment with highly active anti-retroviral treatment also improves HCV symptoms. Dr. Kenneth Sherman (U.S.A.) detailed promising new drugs in the development for treatment of HCV and noted that pegylated interferon would continue as part of treatment in the foreseeable future, as single-drug therapy is less successful due to the high mutagenicity of HCV.

I would like to extend my sincere thanks to all the speakers and presenters who contributed to the success of this congress. Please give us your feedback as to program development for the WFH 2012 World Congress in Paris. ■

Additional coverage of the Hemophilia 2010 World Congress, including the State of the Art papers and the Book of Abstracts, can be found on the WFH website at www.wfh.org.

Coping Skills and Capacity Building Highlighted in Multidisciplinary Sessions

Gordon Clarke

WFH PAST VICE-PRESIDENT PROGRAMS,
CONGRESS MULTIDISCIPLINARY
COMMITTEE CO-CHAIR

Patients, World Federation of Hemophilia (WFH) national member organization leaders, and healthcare professionals offered insight into the many facets of bleeding disorders management at the Hemophilia 2010 World Congress.

WOMEN AND BLEEDING DISORDERS

Despite significant differences in cultural environments and access to care, the keys to providing psychosocial and therapeutic support for women with bleeding disorders are the same: education and outreach. However, promoting acceptance and support does pose additional challenges in some parts of the world. Shirin Ravanbod (Iran) discussed the challenges stemming from prevailing moral, religious, and cultural values that prevent women from talking about their bleeding, particularly menstruation. These cultural factors are compounded by lack of diagnostic facilities and limited knowledge of women's bleeding disorders by medical personnel. Strategies used to promote improved care include better classification and accurate diagnosis of von Willebrand disease, educational seminars for gynecologists, hematologists, and nurses, and outreach programs.

ESTABLISHING A NATIONAL CARE PROGRAM

At the session highlighting WFH programs, it was clear that government health authorities, patients, families, and national and world-wide organizations must all play a role in implementing national care programs to improve health outcomes in patients with bleeding disorders. Twinning programs can help under-resourced countries set guidelines for such programs, said a panel of international experts. With assistance from the World Federation of Hemophilia's Global Alliance for Progress (GAP) program, Thailand implemented its National Hemophilia Care Program in 2004, which has clearly improved patients' quality of life, said Dr. Partraporn Isarangkura. Hospital admissions and length of stays have decreased significantly, and 78% of patients and their families report a greatly improved quality of life. In Jordan, implementing an effective national program has had a measurable impact on factor VIII concentrate usage per capita, said Dr. Arafat Awajan. Dr. Haghine Khachatryan (Armenia) emphasized the importance of treatment centre twinning in promoting information exchange among medical professionals, and Dr. Marta Monteros (Mexico) pointed out that having an accurate country-wide patient registry makes it much easier to calculate treatment needs at a national level.

In the nursing pre-congress session, Carmel Egan (Ireland) traced her team's

development of a nursing care plan for patients with bleeding disorders.

HELPING CHILDREN COPE

"Why my child?", and "How will we cope?" are the first questions that come to mind for parents who learn that their child has a bleeding disorder, César Garrido, treasurer of the Venezuelan Hemophilia Association (Asociación Venezolana para la Hemofilia), reminded attendees. Thankfully, nowadays parents can rely on an established set of strategies and support networks to protect their children and improve their quality of life. The most immediate coping strategies involve understanding the disease, learning about available treatments, and teaching children to participate in their own care. Be honest and explain the condition as early and as fully as possible, Gordana Stevanovic (Serbia) recommended. By actively participating in local hemophilia organizations, families can get the information they need, meet others who share the same experience, and connect with experienced healthcare providers.

SPORTS AND PHYSICAL ACTIVITY

While participation in sports can help build physical strength, improve musculoskeletal health, and increase self-esteem and a sense of belonging, deciding to engage in sports can be difficult for children with bleeding disorders and their families, who must weigh the risks and benefits carefully.

LEFT: Delegates attending a session RIGHT: Gabriel Lottaz presenting at a session on Living with a Rare Bleeding Disorder



According to Andrés Thomas (Argentina), families should consult with professionals while their children are young to find the sport that best fits their circumstances. "Hemophilia is a chronic condition, and expectations are different in each age group," physiotherapist Nichan Zourikian (Canada) said. Younger children need to make friends, adolescents have other interests, and adults may need the cardiovascular benefits of sports. Dr. Sylvia von Mackensen (Germany) presented the results of three studies assessing the impact of sports in children's quality of life.

LIVING WITH A RARE BLEEDING DISORDER

People living with a rare bleeding disorder often face significant challenges both in terms of getting an accurate diagnosis and proper management. Latifa Lemhene (Algeria) described her first 19 years as "a period of ignorance for me, my family, and the doctors." A diagnosis in 2001 of combined factor V/factor VIII deficiency was the catalyst for her to translate a lifetime of severe bleeding episodes into a mission for action. Two years later, Lemhene formed a hemophilia association in her community and eventually became president of the Algerian Hemophilia Association. As a person with afibrinogenemia, or factor I deficiency, Gabriel Lottaz (Switzerland) lived through similar challenges, and he too transformed his diagnosis into action, becoming president of the Swiss Hemophilia Association.

AGEING WITH HEMOPHILIA

Although life expectancy for people with hemophilia increased from 7.8 years in 1939 to 70 years in 2001, the average masks a difference in experiences in developed and developing countries, probably best illustrated in it not being possible to find an elderly person from a developing country to participate in sessions. As Anil Lalwani (India) pointed out, "life is still hard for a child with hemophilia in India, so imagine their situation when they pass into their fifties." As they age, patients are at risk of co-infection, disability, and serious mobility problems, all of which lead to early retirement and significant loss of income, which constrain their ongoing

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Global NMO Training in Pilar, Argentina

WFH Global Training for National Patient Organizations Focuses on the Future

Sarah Ford

WFH COMMUNICATIONS MANAGER

Patient organizations from 86 countries, totaling 102 participants, gathered in Pilar, near Buenos Aires, from July 7 to 9 for the sixth Global Training for the World Federation of Hemophilia (WFH) national member organizations (NMOs). With sessions targeting youth issues, new online technologies, and clinical research, this year's meeting focused on looking to the future.

"There was active involvement from the youth delegates in helping shape discussions on key issues," said César Garrido, WFH past vice-president NMO. "We are very pleased with the excellent participation, throughout the training, from all delegates involved."

WFH president Mark Skinner and executive director Claudia Black updated participants on the organization's new strategic goals. These include developing programs for youth, using new communications technologies, developing a new research program for the WFH, and preparing for the WFH's 50th anniversary in 2013.

Participants in the youth session explored themes that concern their age group as well as the challenges patient

"Young members are integral to the future of NMOs," said Deon York, president of the Haemophilia Foundation of New Zealand

organizations face in trying to engage and prepare future leaders for the bleeding disorders community.

Travel grants were provided to 15 youth to attend this training. In addition, one young woman from Algeria, who received a Susan Skinner Memorial Fund Scholarship, also attended the training.

"Young members are integral to the future of NMOs," said Deon York, president of the Haemophilia Foundation of New Zealand. Yet many hemophilia organizations have trouble engaging them.

Suggestions for how to attract young people included making activities more interesting and relevant, as well as providing guidance and mentoring to help them understand their role and overcome fears of failure.

The program also included sessions on clinical research, online communications strategies, conflict resolution, organizing events, cooperation with local organizations, and a discussion of the challenges and opportunities of the WFH twinning program. ■



Physiotherapy in the treatment room

Advocacy in Action

A new chapter in WFH advocacy initiatives

Gordon Clarke
WFH PAST VICE-PRESIDENT
PROGRAMS

Dedicated Healthcare Professionals Ensure Congress Participants Have Access to Treatment

Lucianne Bannerman
WFH PROGRAM OFFICER, HUMANITARIAN AID

As part of its commitment to congress participants who do not have access to treatment products, the World Federation of Hemophilia (WFH), working in partnership with the Fundación de la Hemofilia of Argentina, organized a treatment room, accessible throughout Congress. Clotting factor concentrates used to provide treatment for patients at the WFH's major events—Global NMO Training, Congress, and the General Assembly—were graciously provided by Baxter, Biotest, CSL Behring, Grifols, Kedrion, Novo Nordisk, Pfizer, and Talecris.

Donations totaled 904,880 International Units and 50 mcg. The donated product helped provide 240 treatments to 86 patients from 44 countries.

With their unparalleled organizational skills, the Fundación de la Hemofilia of Argentina played a vital role in ensuring the successful preparation and running of the treatment room.



Patient receiving clotting factor concentrate in the treatment room

With their unparalleled organizational skills, the Fundación de la Hemofilia of Argentina played a vital role in ensuring the successful preparation and running of the treatment room.

A team of dedicated doctors, nurses, and physiotherapists were assigned by the Fundación, on a rotating schedule, to monitor the treatment room and provide care to patients in need. They were available throughout the day and were also "on-call" outside the treatment room's designated hours. A physiotherapy room was also available for immediate care. The integration of physical therapy consultation, in conjunction with accessing treatment products, enables a comprehensive approach to treatment.

One delegate was particularly impressed and grateful for the treatment room's excellent commitment to patients in need. Following a knee bleed during Congress, he was provided with a pair of crutches, ensuring a comfortable Congress experience and journey home to Sudan.

The WFH would like to thank our donors for their ongoing commitment to making the Congress treatment room a reality. We would also like to extend a heartfelt thank you to the Fundación for the excellent service they provided on our behalf. ■

During the Global NMO Training, the World Federation of Hemophilia (WFH) announced the start of a new advocacy program. The first four WFH advocacy training workshops ran from 2006 to 2010, with 86% of participating WFH National Member Organizations (NMOs) fully or partially achieving their action plans. Based on this feedback, the WFH will begin a new advocacy program, Advocacy in Action.

The Advocacy in Action program will continue to assist WFH member organizations in perfecting their advocacy skills. Tailored, theme-based advocacy support will include workshops, the creation of support tools, an individualized coaching program, and a dedicated WFH staff member to assist with the implementation of advocacy action plans.

In addition, advocacy project grants will be provided to some NMOs. These grants will support projects and campaigns to strengthen the capacity of national member organizations to become more effective and successful in advocating for improved care.

Additional support will include a page on the WFH website that will provide details and information on the advocacy program as it develops. Also, an "Advocate of the Year" award will be given for best practices by a member organization for their advocacy projects and campaigns.

The Advocacy in Action program is set to begin at the end of 2010. Twelve workshops will be conducted over a four year period. The combination of workshops and the individualized and focused coaching support, coupled with the financial support to supplement local costs, will strengthen the capacity of WFH member organizations to advocate effectively. This in turn will help each country to lobby governments to improve and sustain care for people with bleeding disorders. ■

The WFH is grateful for the multi-year support of the Advocacy in Action program provided by Baxter.



LEFT: Delegates at the WFH General Assembly RIGHT: Voting in new National Member Organizations

Delegates at WFH General Assembly Welcome New National Member Organizations and Executive Members

Claudia Black

WFH CEO AND EXECUTIVE DIRECTOR

Held on July 15, 2010, following the XXIX World Hemophilia Congress in Buenos Aires, the World Federation of Hemophilia (WFH) General Assembly was attended by delegates from 96 national member organizations.

Three national patient organizations from Botswana, Eritrea, and Sudan were voted in as full member organizations, and five national organizations from Bolivia, Ethiopia, Ghana, Suriname, and Tanzania were voted in as associate member organizations, making the WFH a truly international organization with members from 118 countries around the world.

Martin Boakye, president of the Ghana Haemophilia Society, was excited to be welcomed to the WFH: "Accreditation puts Ghana on the map of the bleeding disorders world. We will receive recognition and possibly more support, which will help our members be exposed to education and advocacy, giving hope to the young boys and men currently suffering in my country."

One of the many important decisions made by the member organizations was the vote to endorse the WFH Resolution on the Supply of Safe High-Quality Clotting Factor Concentrates, stating the unified position of the WFH regarding the safety of clotting

One of the many important decisions made by the member organizations was the vote to endorse the WFH Resolution on the Supply of Safe High-Quality Clotting Factor Concentrates

factor concentrates derived from remunerated as well as non-remunerated blood and plasma donations. The passing of this resolution will be a cornerstone to ensure the continued availability of treatment products for our community.

Another highlight from the General Assembly was the vote for the site of the 2014 WFH Congress. Representatives from the U.S.A. (Miami) and Australia (Melbourne) presented their bids to host the 2014 WFH World Congress, with Australia selected as the host country.

New and returning executive committee members were elected: Dr. Nigel Key (U.S.A.) was re-elected as a medical member, and Dr. Alok Srivastava (India) was elected as a medical member. Deon York (New Zealand) and Thomas Sannié (France) were elected as new lay members. Eric Stolte (Canada) and Dr. Magdy El Ekiaby (Egypt) were co-opted onto the WFH Executive Committee following the General Assembly.

I would like to thank the three executive committee members completing their terms for their tremendous commitment, hard work, and greatly appreciated involvement over the years. Gordon Clarke (U.K.), vice-president programs, has been involved in the international hemophilia community for over 12 years. During this time, he participated in important initiatives, including the WFH Strategic Plan and regional NMO advocacy training workshops. His hard work and dedication have impacted the lives of many people living with bleeding disorders around the world. César Garrido, vice-president NMO, joined the Executive Committee in 2002. Through his work, he helped develop many national member organizations, and served as a lead WFH volunteer in Latin America, traveling throughout the region in addition to his global responsibilities. Dr. Angelika Batorova (Slovak Republic) has been on the Executive Committee as a medical member for four years, and made a significant contribution to the level of diagnosis and treatment of bleeding disorders in many countries in Eastern Europe.

I would also like to take this opportunity to thank all our national member organizations and the many volunteers whose support and hard work have helped the WFH achieve its goals and make its programs successful. Your dedication and commitment make a world of difference. ■

The WFH Recognizes Outstanding Volunteers from Around the World

Ellen Reid

WFH COMMUNICATIONS OFFICER

The World Federation of Hemophilia (WFH) recognized outstanding volunteers from around the world in the WFH Awards Ceremony held at Congress. This ceremony was hosted by Aris Hashim, chair of the Awards Committee and a member of the WFH executive.

Antonia Luque de Garrido, General Coordinator of the Venezuelan Association of Hemophilia (AVH), won the International Frank Schnabel Volunteer Award. Over the last 20 years, Antonia has helped improve

Health Organization and presented the WFH's case for keeping factor VIII and IX on the Essential Medicines List.

The WFH's newest award was won by **Hemophilia of Georgia**. The International Outstanding Service Award recognizes an individual or organization that has demonstrated leadership, commitment, and active dedication to serving the bleeding disorders community and furthering the WFH's mission. Hemophilia of Georgia is the WFH's volunteer pharmacy and acts as one of our principal storage and dispatching centres for product donations, with its staff providing invaluable support to the WFH Humanitarian Aid Program since 2000. In

notably contributed to furthering the mission and goals of the WFH Musculoskeletal Committee. **Lydia Abad-Franch**, from Spain, was awarded Henri Horoszowski Award, selected by the Musculoskeletal Committee for the best musculoskeletal paper presented at Congress, for her paper "Influence of an Aquatic Training Protocol on the Reduced Risk of Cardiovascular Morbidity and Mortality in a Hemophiliac".

The Twins of the Year Awards are given annually by the WFH to recognize the most exceptional organization and treatment centre twinning partnerships. This program pairs hemophilia organizations or medical centres in developing and developed



LEFT TO RIGHT: WFH president Mark Skinner with Antonia Luque de Garrido; Twins of the Year recipients; Awards

access to care and treatment for the bleeding disorders community in Venezuela and Latin America as a whole. Through her advocacy efforts, Venezuela has become the country with the highest treatment level in her region.

The International Healthcare Volunteer Award was received by **Dr. Mammen Chandy** (India). Dr. Chandy is a leading hematologist who has been actively involved with the Hemophilia Federation of India for many years. Through his work with the WFH, Dr. Chandy was instrumental in drawing attention to the realities of people living with bleeding disorders in the developing world. He was also the WFH liaison with the World

2004 alone, they received and dispatched over 50 million International Units of treatment products to countries in need.

Nichan Zourikian, a physiotherapist from Canada, was awarded the Inga Marie Nilsson Award. Nichan has been heavily involved in musculoskeletal activities, including the WFH Musculoskeletal Committee and world congresses. He has contributed to numerous WFH training workshops in many countries in Africa, Asia, and Eastern Europe, and is an active volunteer for the Canadian Hemophilia Society.

Dr. Horacio Caviglia (Argentina) was the winner of the Pietrogrande Prize. This prize recognizes a healthcare professional who has

countries to encourage the transfer of skills, resources, and information.

The Treatment Centre Twins of the Year Award for 2008 went to **Penn Comprehensive Hemophilia and Thrombosis Program**, and the **Children's Hospital of Philadelphia**, USA, and the **Princess Marina Hospital HTC**, Gaborone, Botswana. The Organization Twins of the Year Award went to the **South African Hemophilia Foundation** and the **Canadian Hemophilia Society**.

There were two sets of Treatment Centre Twins for 2009: **Christian Medical College Vellore**, India, and **Lady Ridgeway Children's Hospital**, Colombo, Sri Lanka; and the **Institute of Hematology and Blood Transfusion**,



LEFT: Dr. Fatmah Abdallah, winner of the free WFH Membership draw RIGHT: Donation box at the WFH Resource Centre

Warsaw, Poland, and the **Republican Functional Hemophilia Treatment Centres for Adults and Children**, Chisinau, Moldova. The Organization Twins awards were won by the **Hemophilia Association of Peru** and the **Galician Association of Hemophilia** (Spain).

The Susan Skinner Memorial Fund Scholarships for 2010 were awarded to **Salima Hadjammar** (Algeria) and **Danielle A. Schwager** (USA). One of the 2009 recipients, **Mallory O'Connor** (USA), was also recognized during the Awards Ceremony.

Dr. Kenneth G. Mann was selected for the Henri Chaigneau Prize by the

Making a World of Difference at Hemophilia 2010 World Congress

Dolly Shinhat-Ross
WFH DEVELOPMENT DIRECTOR

The WFH would like to extend a tremendous thank you to the 350-plus delegates in Buenos Aires who participated in our Make a World of Difference fundraising campaign at Congress.

To make Treatment for All a reality, delegates made donations totalling over US\$10,000—a record for a World Federation of Hemophilia (WFH) congress. Ranging from one peso to one thousand U.S. dollars, these gifts will help provide sustainable care to people with bleeding disorders the world over. Donors put a pin into their country on a map of the world and were given a unique congress lapel pin.

There were also a number of prize draws:

Daily prizes were won by Hamlin Casas (Venezuela), Martin Boakye (Ghana), Soledad Rivero Haedo (Argentina), and Gerard O'Reilly (Ireland).

The Grand Prize (a trip to Congress 2012 in Paris) was won by Dr. Rahajuningsih Dharma, secretary of the Indonesian Hemophilia Society.

The WFH International Donation World Cup was awarded to Canada for the most donors at Congress, a total of 42.

In addition, New Zealand was acknowledged for the most donors per capita, 14 donors relative to a total population of 4,252,277.

Donors are invited to look for their photo at the WFH Map in the Congress 2010 photo gallery at www.wfh.org.

A total of 38 delegates from 18 different countries chose to support the WFH through new membership—a first at Congress!

Dr. Fatmah Abdallah of Kenya was the winner of a free WFH Individual Membership and complimentary 2011 subscription to *Haemophilia*, the official journal of the WFH. Thank you to Wiley-Blackwell for providing the subscription.

You can sign up for membership and make donations online at any time under 'How You Can Help' at www.wfh.org, or use the envelope included in this publication.

Thank you to all the volunteers who assisted with Fund and Resource Development activities at Congress. ■

Thank you

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Gracias

Мерси

спасибо

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French Association of Hemophilia. Dr. Mann was recognized for studies aimed at understanding the fundamental process of hemostasis, and work that has contributed to the pursuit of new technologies aimed at advancing therapies for hemophilia patients.

Congratulations to all the recipients of the 2010 awards. ■

For full coverage on the Awards Ceremony, visit www.wfh.org. More information on the awards and the recipients will also be included in the upcoming issue of *WFH Volunteer News*.



Thank You— Gracias

Craig T. McEwen

WFH DIRECTOR CONGRESS AND MEETINGS

Hemophilia 2010 World Congress would not have been possible without the hard work and determination of a dedicated group of local volunteers. Special recognition needs to be given to the Congress host, the Fundación de la Hemofilia of Argentina, for their time, effort, and devotion in helping to ensure the undeniable success of the Congress. Over the past four years, the Fundación's staff and members have dedicated themselves to this mission, working long hours and spending time away from their families and friends to help ensure that congress attendees could have the best experience possible.

The dedicated treatment room staff, present at the Global NMO Training, Congress, and the General Assembly, worked tirelessly in a professional and compassionate manner. Their state-of-the-art treatment room offered access to treatment and care to those in need.

Hemophilia 2010 World Congress would not have been such a success were it not for the tremendous efforts of the local volunteers that were recruited and trained by the Fundación and their Cultural Program and Volunteer Organizing Committee. Nearly one hundred volunteers, consisting of patients and their families and friends,



TOP LEFT: Thank you to all the volunteers at the XXIX Hemophilia World Congress TOP RIGHT: Fundación de la Hemofilia of Argentina President Carlos Safadi Márquez at the Opening Ceremony ABOVE: Congress volunteers

a local scout troupe as well as students, greeted Congress participants each day with both enthusiasm and compassion. The Organizing Committee helped with visa questions and assisted in the organization of the Opening Ceremony, Cultural Event, and Farewell Dinner.

The WFH is grateful to all the Congress

sponsors. For a full list of these sponsors, go to page 16.

As we close the books on our most successful Congress to date, the World Federation of Hemophilia would like to extend a heart-felt thank you to all who gave their time and dedication—we could not have done it without them. ■

MULTIDISCIPLINARY SESSIONS

continued from page 7

treatment options, leading to further joint damage and infection. Mike Carnahan (New Zealand) said people ageing with hemophilia in his country probably experience fewer problems than they did as children, making it realistic to set the goal of living an independent, fulfilling life. He advocated “physio, physio, and more physio” to maintain health.

In a pre-congress session, Lucie

Lacasse (Canada) discussed the nurse's role in educating patients about proper care in advancing age, and advocating for adequate resources within treatment centres to meet these changing needs.

The WFH World Congress is unique in that it brings healthcare providers from multiple disciplines and patients from around the world together to share their experiences and insight. On behalf of the WFH and the Congress Multidisciplinary Committee, I would like to extend my sincere thanks to all this year's speakers. ■



WFH 2012
WORLD CONGRESS

PARIS, FRANCE

Sunday, July 8 - Thursday, July 12

50
Years of Advancing
Treatment for All



www.wfhcongress2012.org



World Hemophilia Day 2010—The Many Faces of Bleeding Disorders

Hemophilia organizations around the globe proudly celebrated World Hemophilia Day on April 17. This year, a record number of countries—53 and counting—participated. Here are some of the highlights. Read more at www.wfh.org/whd.



Nepal



Venezuela

AMERICAS

Celebrations for World Hemophilia Day in Argentina included a summer camp organized by the **Fundación de la Hemofilia**.

The **Federação Brasileira de Hemofilia** (Brazil), in partnership with the Brazilian Ministry of Health, ran an essay contest for people with hemophilia. The Federation also held a national meeting in São Paulo for patient association leaders.

The **Canadian Hemophilia Society** and its chapters organized information and fundraising events in treatment centres, schools, shopping malls, and other public places across the country.

The **Sociedad Chilena de la Hemofilia** (Chile) launched a solidarity campaign for people with hemophilia who lost their homes in the February 27 earthquake.

More than 180 patients, family members, and other guests attended an evening celebration with performances and hemophilia information, organized by the **Liga Colombiana de Hemofílicos** (Colombia).

Members and supporters of the **Sociedad Cubana de Hemofilia** (Cuba) gathered for a range of cultural and family activities.

The **Fundación Apoyo al Hemofílico** (Dominican Republic) conducted a symposium for 85 health professionals as well as a two-day workshop for 92 lab technicians from major hospitals and clinics.

Representatives of the **Fundación Hemofílica del Ecuador** (Ecuador) conducted a series of educational radio interviews.

The **Asociación Guatemalteca de Hemofilia** (Guatemala) officially opened its headquarters on World Hemophilia Day.

The **Sociedad Hondureña de Hemofilia** (Honduras) conducted a poster campaign in hospitals across the country.

Hemophilia awareness and the need for improved treatment and greater factor concentrate supplies were promoted by the **Federación de Hemofilia de la República Mexicana** (Mexico).

The **Nicaraguan Red Cross** World Hemophilia Day event was attended by 310 people.

The **Fundación Panameña de Hemofilia** (Panama) and its Catalan (Spain) twinning partner held the country's first gathering for youth with bleeding disorders.

The **Fundación de Ayuda al Hemofílico** (Paraguay) celebrated World Hemophilia Day with a social gathering and the acquisition of an ambulance.

Patient and medical representatives from three major Peruvian cities gathered in Lima for educational activities and a hemophilia forum, organized by the **Asociación Peruana de la Hemofilia** and its supporters.

The **National Hemophilia Foundation** (U.S.A.) launched an extensive information campaign using Facebook, Twitter, YouTube, and other social media. Many of the chapters also participated.

The U.S. government's **Centers for Disease Control and Prevention** posted information about hemophilia on its website and supplied links to the WFH video podcast.

A film premiere was organized by the **Asociación Venezolana para la Hemofilia** (Venezuela) and its 11 affiliates on April 16.

Another event was held the following day for children and their families.

EUROPE

Celebrations by the **Hemophilia Society of Bosnia and Herzegovina** included a gathering of members and healthcare professionals.

The **Czech Society of Hemophilia** organized a sport and social program for about 110 children and adults.

Representing more than 500 companies, the **European Diagnostic Manufacturers Association** publicly expressed its support for World Hemophilia Day.

The **Association Française des Hémophiles** (France) and its chapters organized a wide range of activities throughout the country.

The challenges faced by both hemophilia patients and their doctors were examined at a conference attended by about 300 people, organized by the **Greek Hemophilia Society**.

The **Parcelso Foundation** (Italy) organized an open day in Milan and launched a new program that emphasizes quality of life issues for patients, in addition to their medical needs.

The **Latvijas Hemofīlijas Beidriba** (Latvia) translated and distributed hemophilia information material and organized a meeting on bleeding disorders.

AFRICA AND EASTERN MEDITERRANEAN

Events throughout the country, organized by **Association Algérienne des Hémophiles** (Algeria), included children's activities and a large meeting of patients, medical officials, and health professionals.

The **Kuwait Hemophilia Society** celebrated the country's first World Hemophilia Day with an outdoor gathering. Also, the society's national protocol for the management of hemophilia was given official approval on the day.



Iran



USA



China



India



Korea



Italy



Panama

ASIA AND WESTERN PACIFIC

The Haemophilia Foundation of Australia created an information campaign and promoted the WFH video podcast.

The Hemophilia Society of Bangladesh organized an exciting day of rides and water sports at an amusement park outside Dhaka.

Hemophilia groups throughout China held celebrations attended by more than 1400 patients.

Activities by the Hemophilia Federation of India included commemoration of its founder and the WFH founder. Many of the Indian chapters also participated.

Celebrations and activities across Indonesia included a gathering in Medan organized by the Family Support Group.

More than 250 patients, family members, medical professionals, and government officials attended Japan's first national patient meeting in over 25 years.

About 140 patients, family members, doctors, and supporters gathered in Seoul for a special ceremony organized by the Korea Hemophilia Foundation.

The Haemophilia Society of Malaysia and the National Blood Centre held a public forum and concert in Kuala Lumpur.

The Nepal Hemophilia Society and the Mothers' Club, organized a successful fundraising symposium and a blood donation program.

Members of the Haemophilia Foundation of New Zealand organized lunches, dinners, youth sporting events, and fundraising activities across the country.

The Hemophilia Association of the Philippines for Love and Service Foundation and The Philippine Hemophilia Foundation helped coordinate a blood donation drive in Manila.

The Haemophilia Association of Sri Lanka, together with the Haematologists Association raised hemophilia awareness with medical discussions in Sinhala and English on two local TV channels.

The Vietnam Society of Congenital Bleeding Disorders generated significant media coverage with TV appearances, newspaper articles, and online publications.

The Lithuania Hemophilia Association's main event was a pavilion in the central square of Vilnius where children drew pictures on the topic of *Our Hopes for the Future*.

A successful weekend symposium in the historic summer resort of Ohrid was a highlight of celebrations organized by the Civil Hemophilic Association of Republic of Macedonia.

The Netherlands Hemophilia Society held its general assembly on World Hemophilia Day.

The need for a national patient registry, multidisciplinary teams in central hospitals, and guidelines were the main messages of an information campaign by the Associação Portuguesa dos Hemofílicos (Portugal).

Red dye added to the fountains of Bucharest was used by the Romanian Hemophilia Association to symbolize the suffering of hemophilia patients.

The Federación Española de Hemofilia (Spain) expanded its ongoing advocacy beyond hemophilia for improved treatment for people with other inherited bleeding disorders.

A candlelight vigil in Stockholm, Sweden, was held in remembrance of about 80 people who died from HIV or HCV infection.

The Ukrainian Hemophilia Association generated significant media interest in a range of activities highlighting the problems faced by people with hemophilia.

The unveiling of a hemophilia statue in Kerman was amongst the activities and celebrations organized by the Iranian Hemophilia Society.

The Association Libanaise de l'Hemophilie (Lebanon) held four events to celebrate, which included activities for children, youth, and mothers.

April 17 held much significance for the Haemophilia Foundation of Nigeria as it celebrated both World Hemophilia Day and its fifth anniversary.

The Oman Hemophilia Programme organized a workshop for medical and patient representatives.

A family day at a water park and an excursion to the Pakistan-India border were among activities organized by the Hemophilia Patients Welfare Society of Pakistan.

The Sudanese Hemophilia Care Association held a gathering of patients, families, and Ministry of Health officials.



Romania



New Zealand

To view the World Federation of Hemophilia (WFH) "The Many Faces of Bleeding Disorders" video podcast that launched on World Hemophilia Day 2010, visit www.wfh.org/whd.

WE WOULD LIKE TO HEAR FROM YOU!

If you have any more stories from this year, please send them to sford@wfh.org.

The WFH is grateful to Baxter, Bayer, and Novo Nordisk for providing funding to support the World Hemophilia Day website.

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Calendar of Events 2010

EHC Annual General Meeting

22-24 October 2010 – Lisbon Portugal

European Hemophilia Consortium

Tel.: +1 212 328 3746

Fax: +1 212 328 3799

Internet: www.ehc.eu

NHF 62nd Annual Meeting

10-13 November – New Orleans, U.S.A.

Tel.: +1 225-291-1675

Fax: +1 225-291-1679

Internet: www.hemophilia.org

WFH Regulatory Workshop

November 15-17 – Rio de Janeiro, Brazil

Email: mbrooker@wfh.org

52nd ASH Annual Meeting

4-7 December – Orlando, U.S.A.

American Society of Hematology

Tel.: +1 202-776-0544

Fax: +1 202-776-0545

Internet: www.hematology.org



President

Mark W. Skinner

Editorial Committee

Antonio José Almeida
Claudia Black
Craig T. McEwen
Elizabeth Myles
Dolly Shinhat-Ross
Alok Srivastava
Alison M. Street

Editor

Sarah Ford

Editorial Assistant

Ellen Reid

Contributors

Richard Andrews
Lucianne Bannerman
Claudia Black
Gordon Clarke
Sarah Ford
Jennifer Laliberté
Craig T. McEwen
Ellen Reid
Dolly Shinhat-Ross
Mark Skinner
Alison Street
Drew Winchur

Graphic Design

Em Dash Design

Print Production

AS Lithographe

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Contact us at:

1425 René Lévesque Boulevard West
Suite 1010
Montréal, Québec
H3G 1T7, Canada
Tel: +1 (514) 875-7944
Fax: +1 (514) 875-8916
E-mail: wfh@wfh.org
Website: www.wfh.org

HEMOPHILIA WORLD WOULD LIKE TO HEAR FROM YOU!

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

The Editor, Hemophilia World

World Federation of Hemophilia

1425 René Lévesque Boulevard West, Suite 1010

Montréal, Québec,

H3G 1T7, Canada

E-mail: sford@wfh.org