

Very brief snippets of the 2010 WFH World Congress

File 1 - Disclaimer: Following are excerpts, some of which have been extracted from the official newspaper of the 2010 WFH World Congress. Opinions expressed are those of the individuals and organizations cited. I felt that sharing some thoughts and quotes from this newspaper would be a good way to communicate the spirit of information that was shared at the Congress, to those who would not have had the opportunity. Individual's photos taken by Cheryl D'Ambrosio with permission from each person.



Avenue 9 de Julio – Buenos Aires, Argentina

Welcome to Buenos Aires

The XXIX Hemophilia World Congress was held from July 10-14 2010, in the capital of the Argentine Republic where 4,300 participants from 106 countries convened. This is the meeting place of people and cultures where those in the global bleeding disorder community have come to share knowledge, research, advice and experience.

Numerous pre-conference events occurred throughout the week prior to the conference where participants could participate in additional activities. Some are included in this synopsis.

Free Shuttle buses to and from LaRural are available from Congress participants who have booked their accommodations through the Housing Bureau. A 5-day ticket is \$US40.

Saturday evening's opening ceremony featured the style and grace of the Argentinean ballet. Monday evening's cultural event featured local artists providing traditional Argentinean folklore and dance. Food, beverage and tango lessons were offered to participants.



Spotlight on our host NMO

With programs and services dating back to 1944, Argentina's Fundacion de la Hemofilia is a shining example of the frontline effort to deliver on the promise of Treatment for All. Congress President Dr. Raul Perez Bianco, a person with hemophilia, welcomed congress participants. The Fundacion runs nearly two dozen hemophilia care centers across Argentina, including a facility in Buenos Aires that delivers integrated, multidisciplinary care at all hours, every day of the year.

Skinner to address underserved populations in WFH global family

Our family was the focus of WFH President Mark Skinner's address. "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," says Skinner. And the WFH's mission to improve and sustain care "goes beyond hemophilia to incorporate advocacy and support for all people with inherited bleeding disorders."



Mark Skinner, President, World Federation of Hemophilia

Remarkable progress and success 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 disorder, 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 their symptoms are abnormal even though they have a significant impact on their quality of life. Lack of awareness among caregivers often delays proper diagnosis and treatment when they do not 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. Yet some estimates place the incidence of vWD as high as 1.3% of the population.

The number of women reported with bleeding disorders is growing rapidly in some developed countries. The next step is developing innovative tools and strategies that can be adapted to globally accelerate the identification and treatment of women with bleeding disorders. (article: Haemophilia (2010), 16 (Suppl. 5) 1-10).

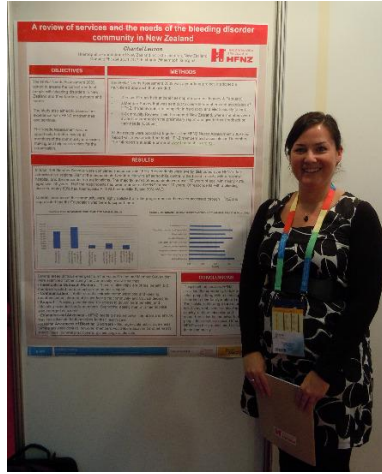
Poster Exhibit

The poster exhibit at this year's Congress features a wide range of topics relating to the diagnosis, management and care of people with hemophilia and other bleeding disorders. This year's presenters will address the latest and most relevant topics facing patients and treaters, including carrier and prenatal issues, prophylaxis, physiotherapy and rehabilitation, clinical trials and clotting factor concentrates, infectious complications and inhibitors, quality of life issues, education and capacity building.

The Congress Program Committee reviewed more than 1,000 abstracts, 745 of which were accepted and were on display in the Exhibit Hall. Authors will be on hand to answer questions on their research during the afternoon coffee breaks throughout the week. To see all poster presentation authors and topics, go to WFH and locate link to the book of abstracts: <http://www.wfh.org/index.asp?lang=EN>



Education and Integration of the Entire Family into Programmes and Activities:
The Irish Experience
Author: Debbie Green, Administrator, Ireland Hemophilia Society
www.haemophilia.ie



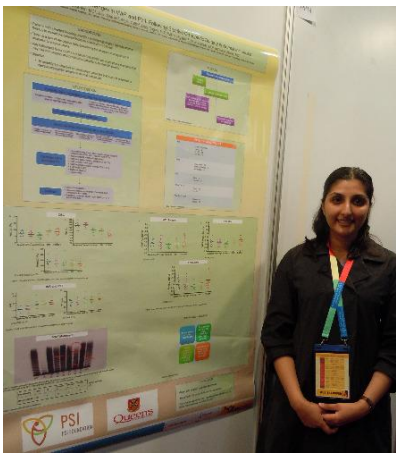
A review of services and needs of the bleeding disorder community in New Zealand
Author: Chantal Lauzon, National Information Coordinator
www.haemophilia.org.nz



Networking of Hemophilia Camps – India
Author: tbd



Promoting knowledge of the illness through information
Fundamental work of the haemophilia associations
Authors: tbd



Implication of changes in vWF and FVIII following elective orthopaedic surgery in
normal individuals
Author: tbd



Achieving more rapid treatment through a high trust network
Authors: Cheryl D'Ambrosio, Art Thompson, M.D., Ph.D.; Seattle, Washington
www.mygirlsblood.org

WFH global training for national patient organizations focuses on the future

Over 100 participants representing patient organizations from 86 countries gathered in Pilar, a small town on the outskirts of Buenos Aires for the WFH 6th Global Training from July 7-9. Through a wide variety of sessions targeting youth issues, new online technologies, and clinical research, the focus of this year's meeting was looking to the future. "Even with treatment products, we can have pain, disabilities and discrimination, explained a young man from Nicaragua. This has a psychosocial impact. You just want a normal life." The WFH provided grants to 16 young people with bleeding disorders to attend the meeting, as part of its leadership program to engage tomorrow's leaders. A critical role for the NMO is to educate patients about new and ongoing clinical trials. Other topics included communication strategies, conflict resolution, cooperating with local organizations, event planning and a discussion of the challenges and opportunities of the WFH twinning program.

Advocacy in Action

The WFH has a new advocacy initiative, *Advocacy in Action*, to continue to assist WFH member organizations in developing their advocacy skills. Tailored training sessions offered both regionally and thematically will include the creation of advocacy tools, an individualized coaching program, and a dedicated WFH staff member to support this training. Advocacy project grants will be provided to eligible member organizations that participated in the training workshops. The new program is set to begin at the end of 2010.

WFH Treatment Room

A bleeding disorder treatment room is located in the Exhibition Hall. Nurses are available to assess emergency and semi-emergency situations to assist with infusions. Hours of operation are throughout the week. Emergency care is available evenings and nights at the offices of the Fundacion de la Hemofilia located near La Rural (the conference area). Clotting factor concentrates used in the Treatment room have been donated by: Baxter, Biotest, CSL Behring, Grifols, Kedrion, LFB, Novo Nordisk, Pfizer and Talecris.

Participants watch surgery in action

Participants had a rare opportunity to observe two live surgical procedures on patients with hemophilia during the pre-congress MSK-ortho session.

In the first, Dr. Horatio Caviglia performed revision surgery on a hip fracture in a 64 year old man with severe hemophilia A and hepatitis B. The surgery was broadcast live from the Hospital General de Agudos “Juan A. Fernandez.” Although the surgical field was extensive, with deep penetration through large amounts of muscle mass, hemostatic control was excellent and bleeding minimal.

In the second surgery, a team used interventional radiology to embolize the genicular arteries in a case of knee synovitis in a 16-year old patient with hemophilia B who had not responded well to other treatments. This relatively simple and less invasive new procedure requires comparatively small amounts of factor replacement and was described as “an exciting alternative to arthroscopic synovectomies in hemophilia patients.”