

Monday, June 1, 2008



Hemophilia
2008 | WORLD
CONGRESS
Istanbul, Turkey
June 1-5, 2008

HEMOPHILIA DAILY

Sponsored by Baxter



A vibrant ensemble of Turkish musicians and dancers entertained delegates at the opening ceremony of the largest-ever Hemophilia World Congress

Welcome to Istanbul

The only city in the world to span two continents, Istanbul is rich in history, tradition, and culture. Not only does the city mark the junction of Asia and Europe, it also represents the intersection of ancient and modern life. From ancient structures like the Hagia Sofia and Blue Mosque in the Old City to modern businesses, hotels, restaurants, and vibrant nightlife, Istanbul offers delegates many opportunities to enjoy great food, art, culture, museums, and – most enjoyable of all – its warm and welcoming people.

Here are ten tips for making the most of the city.

1 Sample the local cuisine. The best place to start is with a kebab house. This typical Turkish food may be cooked over an open flame, or served in a flatbread sandwich. Be sure to sample Turkish mezes, delightful little appetizers of salads, spreads, cheeses, and vegetables. And be sure to bring friends, as a Turkish feast is always enjoyed best with lots of good company.

2 Spend wisely. The official currency is the New Turkish Lira, worth about EUR 0.49 or USD 0.76. Many shops also accept Euros and US Dollars, as well as major credit cards. There is an ATM machine in the lower level of the Convention Centre and numerous bank machines in the Taksim Square District.

3 Expect good weather. The days are pleasantly warm and there is little risk of rain. But be sure to bring a sweater or jacket if you're out after dark, as evenings are cooler.

4 Set aside time to shop at the Grand Bazaar. Billed as the oldest market in the world, the Kapali Carsi's beautiful arched lanes house thousands of shops, selling everything under the sun. Once something catches your eye, be prepared to haggle pleasantly over a tulip-shaped glass of apple tea.

5 Go for a ride. Taxis are plentiful and quite inexpensive and the drive through the city's twisting, narrow lanes can be an adventure in itself. They can be hailed anywhere. It's handy to carry a business card or piece of paper with your destination on it in case the driver doesn't understand English.

6 Enjoy a relaxing and refreshing break at a Turkish Bath. Soak, steam, or have a massage but remember that the sexes bathe separately and there are usually specific hours for men and women.

7 Cruise the Bosphorous. Relatively inexpensive boat tours let you see the beauty of both the Asian and European sides of the city, while marvelling at how Istanbul's many historic cultures have left their mark on the local architecture.

8 Don't forget to tip. In most hotels and restaurants, service is not included in the bill. A tip of 10% (or more for outstanding service) is customary for most services rendered.

9 See the sights of the Old City. The Sultanahmet District is home to the ancient hippodrome, the Blue Mosque, Hagia Sofia, and many inviting cafes and restaurants.

10 Learn some of the language. *Merhaba* means hello, *teşekkür ederim* is thank you, and *lütfen* is please. 🇹🇷

Pre-Congress Workshops

Women with Bleeding Disorders

The interactive workshop led by Ann-Marie Nazzaro (US) and Clare Cecchini (Canada) focused on outreach strategies for identifying women with bleeding disorders. Participants heard about the range and estimated incidence of bleeding disorders that affect women, from rare factor deficiencies to von Willebrand disease. Panelists spoke about strategies used in different countries and cultural contexts, describing education and outreach efforts, and best practices. Aided by a toolkit developed by the co-chairs, participants worked to identify appropriate outreach strategies and develop an effective action plan for their own communities.

Gene Therapy

After more than a decade of progress, gene therapy remains one of the most sought-after approaches to the treatment of hemophilia. In this new workshop, David Lillicrap (Canada)

described the components of a gene therapy strategy and contrasting findings of two viral vector-mediated approaches to the treatment of hemophilia A in hemophilic dogs. Catherine Manno (US) reviewed outcomes of gene therapy in several human clinical trials conducted to date. Participants also heard about new strategies for gene and cell-based therapies, which are in the early phases of preclinical development.

Coagulation

Coagulation testing is complex and constant monitoring by experienced technologists is essential, even with automated systems. This year's workshop engaged the participation of representatives from companies that supply automated laboratory instruments. Chair Angus McCraw (UK) gave an overview of laboratory quality assurance, while Sarah Brooks (UK) discussed advantages of automation. Industry representatives

also demonstrated some of their technologies.

Orthopedic

Co-chair Adolfo Llinas (Colombia) opened with a session on the development of promising new tools, such as the magnetic resonance imaging (MRI) scoring system for evaluating and monitoring hemophilic arthropathy, and determining appropriate preventive measures. Bjorn Lundin (Sweden) described the development of surgical guidelines, while Gianluigi Pasta (Italy) spoke about the importance of establishing a national registry of joint replacements. Participants also learned about the ongoing work of the International Prophylaxis Study Expert Imaging Group.

Physiotherapy

Participants in the physiotherapy workshop discussed a range of issues related to joint health and muscle function in hemophilia. A panel of international

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Conference preview

More than 4200 delegates from over 115 countries have come together for the largest-ever gathering of the global hemophilia community, both in terms of countries and delegates. There will be many opportunities to hear the most current treatment and research developments about hemophilia and other bleeding disorders.

"Today is a historical day, not just for the people with hemophilia living in Istanbul but for those living all over the world... for hope, for understanding, and for achieving Treatment for All," said Congress President Bülent Zülfikar.

There will also be many opportunities to enjoy the beauty and history of Istanbul and the warmth of the Turkish people. These include a city tour for accompanying persons during the day on Tuesday, and a Tuesday evening outing for all to Topkapi Palace, the home of generations of Ottoman sultans, followed by a sumptuous buffet dinner overlooking the Blue Mosque and Hagia Sofia.

Thursday's Farewell Dinner also promises to be a memorable event, as the pool of the Istanbul Hilton will be transformed into a lavish Turkish spectacle (weather permitting). Guests will be entertained by local musicians after dining on traditional Turkish fare. Tickets are available for USD 75.00 at the registration desk while supplies last. Past experience says this is an event that is not to be missed!

Can we count you in?

Show your support of the WFH and its work in three easy steps:

1. Stop by the WFH Resource Centre in the Exhibit Hall to make a donation in support of Treatment for All.
2. Add your name and wish to our Treatment for All donor wall.
3. Pick up a sticker and wear it to show your support.

All donations will be used to support WFH programs and activities to improve care for people with bleeding disorders worldwide.



Pre-Congress Workshops

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experts described the ongoing development of the Hemophilia Joint Health Score (HJHS) based on modifications to existing scores. Measurement of joint health is critically important, yet few measures currently exist, there is lack sensitivity to small changes, and scores are not formally validated. The session also covered effective muscle exercise programs for people with hemophilia and the development of a teaching tool for new physiotherapists.

Psychosocial

The psychosocial workshop chaired by Richa Mohan (India) and Ruud Bos (Netherlands) focused on skills building, research methods, and counselling. Participants shared global perspectives on psychosocial care while also discussing the different psychosocial care issues in developed and developing countries. Interactive sessions between people with hemophilia and their family members, psychologists, and social workers illuminated some of the psychosocial issues related to hemophilia and approaches for coping with the challenges.

Nurses

The nurses workshop, chaired by Lara Oyesiku (UK), covered a spectrum of nursing issues, with case studies from the clinical setting presented by Elizabeth Paradis (Canada) and Regina Butler (USA), and a caregiver perspective from Dalia Bashari (Israel). Participants also learned about the clinical applications of genetics and the effects of being a carrier on women and their partners. The afternoon sessions focused on pediatric and adolescent issues, sexual intimacy with people with bleeding disorders, and issues related to HIV/HCV. 🌐



Participants in the Pre-Congress Physiotherapy Session watch a hands-on demonstration using a young volunteer

Program Updates

Monday

A1.1 Prophylaxis for Severe Hemophilia

Manuel Carcao will present *Prophylaxis in patients with inhibitors*.

A1.3 Medical Free Paper Session

Peter Collins will present *The importance of maintaining FVIII trough levels above 1% during prophylactic treatment of hemophilia A: using license study databases to answer key medical questions*.

A1.5 Educational Models in Hemophilia Care : A Worldwide Overview of Existing Models

Danna Merritt will present *Mentoring the Parents Empowering Parents (PEP) program to success: developing a mentoring component to the PEP Program*.

A2.4 Sharing a Hard Life: How Hemophilia Affects the Family

Elizabeth Fung will present a health care provider Perspective.

Wednesday

C1.6 The Global Impact of Twinning

Haruna Jibril will not be presenting.

C2.3 Life Stages: Childhood & Adolescence

Christine Harrington will present *The meaning of sporting activity in the context of hemophilia*.

C2.4 Getting Heard without Screaming: The Role of Media

Yuri Zhulev will present *The Role of the Media in Eastern Europe*.

Thursday

D1.1 International Prophylaxis Study Group Final Report

Marilyn Manco-Johnson will not be co-chairing with Victor Blanchette.

D1.5 Multidisciplinary Free Paper Session

Angelika Batorova will present *Menarche and juvenile menorrhagia in girls with inherited bleeding disorders*.

D2.4 Meet the experts: Managing Life with HCV and HIV

This session is cancelled.

PLEASE NOTE:

Delegates at the Congress will be wearing blue or yellow badges. 🌐

Shared dreams, common challenges

“There are no barriers in the hemophilia community: we all share the same dream,” said Shirin Ravanbod from Iran, one of the delegates at the WFH’s capacity building training workshop for patient organization leaders.

One hundred delegates from 79 countries attended the three-day skills training workshop, which ended on Saturday. Although they came from different countries with very different levels of care and resources, participants shared many of the same issues and goals.

Reporting on a survey of 52 national patient groups, Gordon Clarke, WFH vice-president national member organizations, noted “all of these organizations, whether from developing countries or developed countries, face similar challenges, but with cultural differences.” The major challenges faced by most respondents included lack of volunteers, treatment products, government support, and funds.

The WFH provided travel grants for 59 delegates to attend, including 16 youth delegates. This allowed patient leaders to come together, pool their knowledge, and learn from each other. Participants discussed strategies for managing relationships with pharmaceutical funders, getting patient representation on government committees, and motivating volunteers. But, most importantly, they shared their unique experiences and focused on their common challenges.

Explaining to delegates how the hemophilia society in his country succeeded in securing factor concentrates and lobbying its government for improved care, Vladimir Beren, from Russia, captured the spirit of the training workshop: “There is no one way and there is no right way, but with determination and perseverance we can succeed.” 

Sessions to watch for

A1.2 The prevalence of Rare Bleeding Disorders ranges from 1 in 500,000 to 1 in 2 million. As a consequence of this rarity, the type and severity of these deficiencies, underlying molecular defects, and the best ways to manage bleeding episodes are not well established. Find out more about the main features, diagnosis, treatment options, and complications arising from treatment.

Presenters are Flora Peyvandi, Marco Cattaneo, Aida Inval, Philippe de Moerloose, and Marta Spreafico.

The session begins at 11 am tomorrow in the Marmara Room.

A2.6 Those attending tomorrow’s MSK Free Papers Session will hear presentations from around the world on everything ranging from multimedia exercise programs to strategies supporting physiotherapy to radioisotope synovectomies.

Presenters are Rachel Tikinsky, Tariq Sohail, David Stephenson, Elizabeth Brodin, Kaan Kavakli, Mauricio Silva, Sandra Squire, Fatih Dikici, J.A. Tlacuilo-Parra, and Lixia Chen.

The session takes place from 3:00 to 4:30 in the Halic Room.

A2.7 Dental procedures continue to present a significant challenge for people with bleeding disorders. This session will examine quality-of-life issues related to Restorative Dentistry, as well as periodontal care and post-procedure complications and treatments for both adults and children.

Presenters are Elvira Correa, Esra Alpkilic Baskirt, Carmel Egan, Eduardo Rey, and Noraini Yunus.

This session begins at 3:00 in Dolmabahce A.

A2.3 Resources for the treatment and care of people with hemophilia are often scarce, even in developed countries. Experiences from India, Iran, and the United States will illustrate how difficult choices are made and will examine resource allocation and guidelines for decision making.

Presenters are Shirin Ravanbod, Fereydoun A. Ala, Keith Hoots, and Alok Srivastava.

This session takes place in Dolmabahce C, starting at 3:00. 

