

HEMOPHILIA WORLD



First Global Feast a recipe for success

Richard Andrews
WFH Communications Officer

Pilot fundraising project to be adopted as an annual international event.

A rural "sugar shack," an armoury museum, and a gala reception room were among the venues used to celebrate Global Feast, an international event in support of people worldwide with bleeding disorders. The first of its kind, the pilot event was a real international team effort amongst four hemophilia societies and the WFH. Coordinated by the WFH, Global Feast, involved hemophilia communities in Australia, Ireland, New Zealand, and the U.K. to raise awareness and funds for improved treatment and care.

In conjunction with World Hemophilia Day on April 17, Global Feast dinners, lunches, barbeques, and other gatherings were organized by people with hemophilia, their families, friends, and patient associations.

"We're very pleased with the results," says WFH Development Manager Rosalind Franklin, who coordinated the celebration. "Our country partners have done a tremendous job. The stories of individuals participating in their small towns and at their workplaces have been so inspiring."

The idea for Global Feast was developed at the WFH Congress in Bangkok, in October 2004. The plan was to make it easy for anyone to help others around the world in need. People were asked to host a Global Feast party for friends, family, and colleagues and to invite their guests to make a donation to support people with bleeding disorders. Dozens of events raised thousands of dollars to be shared between the WFH and the four participating national hemophilia organiza-



Debbie Green and Margaret Dunne prepare information materials for Dublin's Global Feast.



Celebrity chef Gabriel Gate with Global Feasters in Melbourne.



London's gala Global Feast reception.



Canadian Hemophilia Society members celebrate Global Feast in a Quebec "sugar shack."

tions. Proceeds will be used to provide treatment products to people in urgent need, to educate families about hemophilia, and to train doctors and nurses in some of the world's poorest regions.

A Global Feast highlight in **Australia** was lunch in a Melbourne riverside restaurant with Gabriel Gate, a celebrity chef who has sold over one million cookbooks. The gathering was hosted by Haemophilia Foundation Australia, which also held a fundraising raffle. "Guests enjoyed an afternoon of fine food and drink, while listening to Gate's account of his own 'global feast' experiences," says Development Manager, Natashia Coco.

Clubs and associations across Australia also hosted morning and afternoon teas in support of Global Feast. For example, the Country Women's Association in the New South Wales city of Dubbo held a community morning tea. The Association encouraged

the participation of local businesses by taking orders and making deliveries.

The **WFH head office** in Montreal hosted a "sugar shack" excursion, a popular Quebec activity in spring when maple trees are tapped for their sweet sap to make maple syrup. More than 40 visitors gathered at the Sucrerie Mont-Bleu, a rural "sugar shack," for a traditional Quebecois meal and wagon ride around the farm.

Says organizer Laurie Blackstock, "Global Feast celebrates that we're a worldwide community that cares for one another. I'm glad that the money raised here in Canada will be shared with people facing hardships in all corners of the world."

The **Irish Haemophilia Society** organized a coffee morning, afternoon tea, and other events including a dinner at a Dublin hotel for 100 guests. The event was hosted by Brian Geraghty, a well-known footballer. "The Irish Hemophilia Society will use our

(Continued from page 1)

part of the proceeds for twinning activities with Bosnia and Herzegovina," says Administrator Margaret Dunne.

One of the guest speakers was former WFH president Brian O'Mahony, who outlined the Federation's developing world programs and how they help to improve the lives of people with hemophilia through sustainable progress.

O'Mahony was also a guest speaker at a function held earlier by Haemophilia Foundation **New Zealand** (HFNZ). The Foundation used Global Feast as part of a campaign to win compensation for members infected with hepatitis C. HFNZ volunteers, staff, and patients attended a dinner at the Beehive, home of the New Zealand Parliament. The gathering was also addressed by Ruth Dyson, the New Zealand minister responsible for disabilities and medical compensation.

The event was linked to a well-publicized conference on hepatitis C compensation and other activities surrounding World Hemophilia Day. O'Mahony and Irish medical compensation expert Raymond Bradley have been helping HFNZ lobby for compensation.

"Global Feast has given us a platform to demand and get attention," says Dave McCone, HFNZ President. "We feel confident that this event has actively supported our goals, and we are glad to have been a part of it."

The **U.K. Haemophilia Society** held a gala dinner and auction at the prestigious New Connaught Rooms in London for patients, society representatives, health professionals, and industry. Speakers included WFH Vice President Medical, Dr Paul Giangrande, who described the contrast between care in the U.K. and the developing world, where adequate treatment is not available to most patients. Graham Whitehead, the Society's Chief Executive, described the need for continuing support in the U.K., particularly for the most disadvantaged, and for the undiagnosed populations with von Willebrand disease and other bleeding disorders.

Elsewhere in the U.K., groups organized numerous dinner parties, tours, and other events. These included a luncheon talk in Leeds at the Royal Armouries Museum on the appropriate theme of "blood."

Apart from being a lot of fun, the success of the pilot project has encouraged the WFH to expand Global Feast and make it an annual event. ■

Surprising results from Denmark's von Willebrand awareness campaign

*Dorthe Lysgaard, CEO and Lise Johansen, Organizational Officer
The Danish Hemophilia Society*

The Danish Hemophilia Society revisits existing research, methodology, and criteria for diagnosing von Willebrand disease (vWD) following recent evaluation of a national awareness campaign.

Analysis of the Society's 2002 national campaign shows conflicting and surprising results. The campaign attracted much public attention and significantly increased vWD awareness among general practitioners and gynecologists. However two years after the peak of the campaign, only 10 more people had been diagnosed with vWD, far fewer than expected.

At the onset of the campaign only 270 people had been diagnosed with vWD in Denmark, that is 0.00006 per cent of the population. According to international studies, the prevalence of vWD is around one per cent. Therefore, we concluded that many cases were not being properly diagnosed and treated.

Prior to the campaign, a survey of 230 general practitioners and gynecologists showed that many considered vWD a very rare disease and more than one-third of respondents knew little about diagnosis and treatment. In response, the campaign targeted its information material at general practitioners and gynecologists, as well as women aged 15-49, the group most affected by vWD.

The articles, flyers, and news releases caught the public eye and an evaluation survey last year showed a significant increase in knowledge of vWD symptoms and treatment among general practitioners and gynecologists. Despite this raised awareness, the number of people diagnosed with vWD has not increased significantly. Of 800 people referred for vWD testing from 2002-2004, only 10 were diagnosed with the disorder.

The low number of diagnoses has provoked much speculation. One possibility is that the campaign's effects may take time to emerge. As the gatekeepers of the Danish health care system, general practitioners are often reluctant to refer patients to the

specialized diagnostics and treatment required with vWD. Changing this approach may take years.

However, the results have also made us look critically at the existing vWD research, the methodology, and the criteria for diagnosing vWD. Although one per cent of the population lives with vWD the question remains whether all these people "suffer" from the disorder to the degree that they would be considered "ill" in medical terms. This question is much debated and has resulted in different criteria of diagnosis both within Denmark as well as internationally.



Cover of pamphlet used in Denmark's vWD awareness campaign.

When considering a follow-up to the campaign, we must bear in mind the risk of expanding the scope of the disease to include people who might not experience inconveniences in their daily

lives. This should be weighed against concern for the people who could achieve a higher quality of life with the right diagnosis and treatment.

The Danish Hemophilia Society would like to hear of experiences with similar initiatives in other countries.

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GAP keeps growing

Claudia Black
WFH Program Director

The WFH's Global Alliance for Progress (GAP) in hemophilia development project marks its second anniversary and extends hemophilia care further.

Azerbaijan and Jordan have now joined the GAP family bringing the total number of GAP participating countries to nine. With 3,600 new patients identified since the project started, GAP is well on the way to meeting its target of 7,000 new patients for the first nine countries.

"Enthusiasm and collaboration between government, healthcare providers, and patients have been evident throughout all GAP countries," says WFH President, Mark Skinner. "The project is providing a tremendous catalyst to advance care. I visited Jordan in January to sign a GAP agreement with the health ministry and was impressed by the tremendous commitment demonstrated for the project. Clearly, Jordan is well poised to be another leader in hemophilia care."

The WFH launched the 10-year GAP project in April 2003 to close the gap in hemophilia care between developing and developed countries. The World Health Organization (WHO) and our patron, Jan Willem André de la Porte, have been involved in the project, as have Baxter, Bayer, and ZLB Behring.

GAP aims to greatly increase the diagnosis and treatment of people with hemophilia in about 30 developing countries.

To reach these goals, the WFH helps develop new national programs for hemophilia care, training, and education.



WFH volunteer Kathy Mulder conducts a passive exercises workshop in Alexandria, Egypt.

Significantly, five governments have signed formal agreements with the WFH to increase resources for hemophilia care and the purchase of treatment products in their countries. In addition, reports from patient associations in GAP countries say the project has motivated and unified their hemophilia communities.

"Each time I meet a patient or family it's clear GAP is making a difference," says Skinner. "Whether it's providing an accurate diagnosis, data to support health care expenditures by governments, or access to life-saving treatment and care, patients are benefiting from the success of this project. On average, we are now identifying and diagnosing five new patients with hemophilia each day."

The president of Mexico's national hemophilia association, Martha Monteros de Hernandez, says GAP has boosted cooperation amongst the country's diverse and widely spread medical communities. "For example, the project has encouraged the established medical centres to support training programs designed to reach out to people from distant regions," she says. "GAP has done a lot to help people with hemophilia in my country."

The first GAP countries were Egypt, Georgia, Mexico, and the Philippines, followed by Armenia, Russia, and Thailand. Target countries are chosen regionally from

the Americas, Asia, Europe, and the Middle East. GAP complements its programs in target countries with training, education, and information materials that reach out to the entire hemophilia community. For example, countries such as Iran are accessing GAP information on the WFH website to implement their own development projects, using the tools and model we've developed.

GAP has spread further in other ways as well. A new international quality control program to improve laboratory diagnostic standards was launched jointly with WHO, and 65 centres around the world are now involved. Another part of the GAP effort is a new publication called *Guidelines for the Management of Hemophilia*. Developed by WFH medical volunteers, the guidelines provide standard protocols to ensure that hemophilia is properly managed.

One thing is clear on GAP's second anniversary: step-by-step, we are closing the gap for the 75 per cent of the world's hemophilia population living without adequate treatment and appropriate care. ■

Building for the Future

Mark Skinner
WFH President

WFH activities for 2005 are well under way. In January, the Executive Committee approved a robust program of activities to maintain and build the Global Alliance for Progress (GAP) in hemophilia project, country programs, communications activities, and public policy initiatives during 2005. At the same time, we must continue to plan for our financial future and the funding of our increased efforts to improve hemophilia care and treatment around the world.

The immediate challenge is to ensure the continued financial strength of the WFH. Our number one goal for 2005 is to "establish a secure financial base." In addition to addressing our ongoing financial needs, we must diversify our revenue base.

Despite strong financial results from our recent World Congress, the WFH will still be CDN \$150,000 in deficit for 2004. The most significant change in revenues over the past year has resulted from the strength of the Canadian dollar against the U.S. dollar. As the vast majority of contributions arrive in U.S. dollars, we have to increase revenues by CDN \$850,000 over fiscal years 2004 and 2005 just to maintain our services.

Additionally, consolidation and market realignment in the clotting factor industry reduced support from some of our traditional donors in 2004. Therefore, prudent business practices require us to make more conservative sponsorship revenue projections for 2005. To maintain our programs in the long term, the WFH has reduced its current annual budget by approximately 25 per cent.

The WFH is financially strong and positioned well to manage these recent events. The good news is that some of the new fundraising initiatives outlined below have already sparked new enthusiasm for supporting our programs in 2005 and beyond.

To build for the future, the WFH is working to diversify our sources of revenue. We are optimistic about opportunities ahead and the enthusiasm from our corporate partners to support our efforts to diversify funding. The WFH's National Member Organizations have approved the necessary constitutional changes to enable the WFH to become a registered charity. This will streamline and enhance our fundraising ability.



Several initiatives are already under way to:

- Cultivate new corporate partnerships and collaborations outside the pharmaceutical industry
- Hold a global fundraising event with the involvement of National Member Organizations. On April 17, we piloted the first ever such event, the Global Feast
- Approach international organizations to establish program collaboration
- Increase foundation and trust support
- Expand sponsorship opportunities, consistent with the WFH corporate relations policy, to enhance collaboration with existing and new donors
- Establish a major gifts committee to identify, cultivate, and develop long-term relationships with individuals, corporations, and foundations who can donate on an annual basis
- Develop additional affiliated charities in targeted countries similar to the humanitarian arm of the WFH located in the U.S., WFH U.S.A.

These long-term goals will take a sustained commitment from all of us. To date, the support from the many stakeholders in the global hemophilia family has been positive. Despite the budget restrictions, the WFH will continue to conduct many successful activities in 2005. ■

Recent developments with anti-inflammatory drugs

Dr. Paul Giangrande
WFH Vice President Medical



Current recommendations on COX-2 inhibitors.

Many people with hemophilia and related conditions develop arthritis in several joints as they get older. This arthritis is due to chronic inflammation from repeated bleeding into the joints. Because of side effects of many drugs, the choice of medication for people with hemophilia to relieve the pain and swelling associated with arthritis has been limited.

All those with hemophilia should already be well aware of the need to avoid aspirin (ASA) and non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen. These drugs can prolong bleeding by slowing the function of platelets (tiny cells in the blood that help clotting). NSAIDs irritate the gastrointestinal tract (stomach, gut) less than aspirin and other similar drugs. Paracetamol (also known as acetaminophen) is a perfectly safe alternative for pain relief of simple headaches, but unfortunately it is not a strong anti-inflammatory drug.

The development of a whole new class of NSAIDs called COX-2 (cyclo-oxygenase) inhibitors only a few years ago was a welcome advance. These products are just as effective at reducing inflammation as other NSAIDs but do so without affecting the clotting activity of platelets. Many people with hemophilia have found these drugs reduce pain and increase mobility.

The most widely used of these new drugs was rofecoxib (perhaps more familiar by its trade name, Vioxx). However, clinical reports showed that a small number of patients receiving this drug suffered heart attacks and strokes from blood clots blocking blood vessels. As a result, the manufacturer voluntarily withdrew the drug from the market in September 2004 and it is no longer available. The overall risk of thrombosis (blood clot formation within a blood vessel) is much smaller than might be imagined from all the media attention. The European regulatory agencies have estimated the risk as being of the order of one extra thrombotic episode per 100 patient years over the rate for no treatment. This means that if a person were to take the drug for 10 years, he would have a one-in-10 chance of a heart attack or stroke he would not normally have had.

Fortunately, there are several alternative drugs in this class of COX-2 inhibitor drugs. These include celecoxib, etoricoxib, valdecoxib, and parecoxib. The important question is whether all drugs in this class, or just Vioxx, have the potential for causing blood clots. Regulatory agencies have recently considered all the evidence and produced helpful guidelines on the continued use of alternative COX-2 inhibitors.

The guidelines recommend that:

- Patients who have diseases affecting the arteries in the heart or brain should not use these drugs. (People with hemophilia seem to be somewhat protected against the development of such conditions and thus relatively few of them should be affected by this restriction.)
- Periodic monitoring of blood pressure is recommended in patients receiving these drugs and anyone with high blood pressure (hypertension) should stop treatment.
- Additionally, the lowest effective dose should be determined for each patient, as the risk may increase with the dosage of the drugs and the length of time they're taken.

The key message is that these drugs have not been withdrawn, but certain precautions should be taken.

For the time being, these drugs can continue to benefit most patients. The good news for those who have stopped taking these drugs is that there is currently no evidence whatsoever of a lasting increased risk of developing vascular diseases such as heart attacks or strokes. Obviously, the regulatory authorities will continue to monitor reports of adverse events very carefully and the WFH will continue to keep you updated on any significant developments. ■

Meeting the challenges of 9/11 and cultural differences

Richard Andrews
WFH Communications Officer

Lahore and Utrecht medical centres reveal the secrets of successful twinning.

“Persistence and a new approach were needed to overcome our obstacles after the attacks of September the 11th,” says Dr. Akhtar Sohail Chughtai of the Lahore Hemophilia Centre, in Pakistan. “Our region was the hot spot. Terrorists were hiding in neighbouring Afghanistan and using the road to Pakistan to reach the rest of the world.”



Dr. Lily Heijnen and Dr. Sohail Akhtar Chughtai at the WFH World Congress twinning presentation.

Following a relationship that dated back to the mid 1990s, the Lahore centre was formally twinned in 2001 with the Netherlands' Van Creveldkliniek University Medical Centre in Utrecht. However, security restrictions after 9/11 disrupted Lahore's training visits to Utrecht, says Dr. Chughtai.

“Many countries imposed very strict visa restrictions on people traveling from Pakistan. Every time we wanted to visit our twin in Holland we faced visa obstacles and long delays. However, we were determined not to allow geopolitical hurdles to hinder our training program, so we requested our friends to visit us instead.”

In response, rehabilitation specialist Dr. Lily Heijnen and physiotherapist Piet De Kleijn made repeated visits from Utrecht to the Lahore centre. Their activities

included a large training workshop last year for about 70 physiotherapists from around Pakistan. “It was very fruitful exercise,” says Dr. Chughtai. “Participants were able to extend support to patients unable to visit our centre and one of the physiotherapists now trains other colleagues. The twinning has created an ongoing improvement to hemophilia treatment and care in Pakistan.”

Dr. Chughtai says his centre was originally advised to find a twin with a similar cultural background, but in this case it wasn't necessary. “The long involvement of Dr. Heijnen and her team with the Indian subcontinent has given them a good insight into the region's religious, cultural, and social systems. In one sense it was an advantage for them to be outsiders. Our people received the visitors from the Netherlands with a lot of respect and a welcoming attitude. Patients took medical advice very seriously because it was seen as coming from people with international expertise.”

By linking hemophilia organizations or treatment centres in developing and developed countries, twinning has improved diagnosis and medical attention for people with hemophilia in many areas. Sponsored by Wyeth, the WFH Twinning Program currently helps 45 twinning partnerships arrange training programs, workshops, and other exchanges.

“Cross-cultural understanding is very important when twinning,” says Dr. Heijnen, “because perceptions of some treatment may differ from one country to another. For example, in the Netherlands and many other countries there's no problem using elbow crutches or other visible aids. Sportsmen and skiers may even show off their crutches proudly after an accident.

“I have long advised patients with bleeds or joint pains to use crutches rather than miss school or work. So when a patient



Physiotherapist Piet De Kleijn conducts a training session in Lahore.

in Pakistan struggled into the centre carrying his 12-year-old brother, I thought there was a shortage of crutches and we needed to send some over. Instead, I was told that people in Pakistan look down on such aids because they're associated with beggars who exploit their disabilities to earn money. We're now looking at a project to change these attitudes. We may use a well-known sportsperson to endorse some specially designed crutches and give them a positive image.

“But overall, I've found that people with hemophilia around the world have more similarities than differences. The most important thing is to listen and then put into practice what you've heard. From a human point of view, the twinning experience has enriched me tremendously.”

Dr. Chughtai agrees. “From our Dutch friends, we've learnt the importance of perseverance for the cause and selflessness. I tell my people that if you want to advance the cause of hemophilia you have to work beyond yourself. You have to be on the giving end. The reward comes when a patient arrives with pain and discomfort but leaves peacefully.”

For more information on twinning visit www.wfhi.org ■

Record numbers expected in Vancouver for 2006 WFH World Congress

Craig T. McEwen
WFH Director, Congress and Meetings

At the start of the 12-month countdown, the WFH World Hemophilia Congress in Vancouver, 21-25 May, is shaping up to be the largest and most exciting to date.



Congress President
Dr. Georges-Etienne Rivard.

Vancouver Harbour is one of the world's most spectacular settings.

A packed and highly diverse program is well under way for Hemophilia 2006 and Vancouver is proving to be the ideal congress destination. Healthcare professionals, people with hemophilia and their families, and national hemophilia organizations will have access to information on the latest advances in hemophilia treatment and care.

"By gathering eminent scientists, doctors and other experts, the WFH congress strengthens the world hemophilia community, raises its profile, and demonstrates its significance," says Congress President, Dr. Georges-Etienne Rivard. "Congress is an opportunity for the hemophilia community to become more effective as an international group seeking improved support from governments, international organizations, and the pharmaceutical industry."

Program sessions will include:

- Gene therapy for hemophilia
- Management of hepatitis C
- Treatment of patients with inhibitors and immune tolerance
- Quality of life studies
- Von Willebrand disease: diagnosis and treatment
- Prophylactic therapy
- Pain management
- Orthopedic surgery

Following the success of the pre-congress sessions at the 2004 Bangkok Congress, similar workshops will be offered in Vancouver. These sessions will give delegates valuable skills and knowledge that they can integrate into their own work and communities. Workshops confirmed so far will focus on laboratory sciences, nursing, physiotherapy, psychosocial issues, and the diagnosis and management of bleeding disorders.

Vancouver itself is a city surrounded by some of the most stunning natural beauty in the world: mountains, ocean, rainforest,

beaches, coastline, and islands. Hundreds of outdoor and indoor activities are on offer from interactive museums and fun festivals to parks and adventure cruises.

Congress organizers have secured group discount rates for the finest hotels, just minutes away from the Vancouver Convention and Exhibition Centre, the congress venue.

Outside Vancouver, the city of Victoria, on Vancouver Island, is a short distance away by ferry and offers visitors spectacular gardens, unique shops and restaurants, scenic cityscape, and heritage attractions. The town of Whistler, home to alpine events for the 2010 Winter Olympics, is a 90-minute drive from Vancouver along the scenic Sea to Sky Highway.

May to September is considered the best time to visit Vancouver and the mild weather in May is ideal for sightseeing.

We hope to see you there!

Visit www.hemophilia2006.org for further information and on-line registration. ■

2005 WORLD HEMOPHILIA DAY

Richard Andrews
WFH Communications Officer

Hemophilia organizations around the world celebrated World Hemophilia Day, April 17, with a wide range of activities, events, and campaigns to promote improved treatment and care.

World Hemophilia Day was started in 1989 as a way to increase awareness of hemophilia and to bring attention to the needs of those affected by the disorder. April 17 was chosen because it was the birthday of WFH founder Frank Schnabel. A different theme is suggested each year for World Hemophilia Day. For 2005 it was: *Get vaccinated! Prevent hepatitis A and B.*

The day has come to mean many things to national hemophilia organizations in different countries. Here's how some of them commemorated the occasion this year:

Argentina celebrated World Hemophilia Day with outdoor events and children's entertainment just outside Buenos Aires in the city of Luján. About 160 patients, families, and medical professionals enjoyed the sunshine with a barbeque, walks, and other activities.

The Hemophilia Society of **Bangladesh** organized a news conference and rally at the National Press Club in Dhaka. Attended by prominent speakers, the events were widely covered by the major daily newspapers and television channels.

Young people with hemophilia in **Ecuador** visited schools to talk about the disorder, as part of an awareness raising campaign.

Brochures were distributed in **Honduras** to inform people about bleeding disorders. Patients and families celebrated the day in Tegucigalpa with a gathering, presentations, and events for children.

Hemophilia associations in **India** continued their record of successful campaigning with high profile events across the country. These included a rally in Mumbai and a walkathon in Bangalore with hundreds of participants carrying placards. Medical experts delivered lectures at a function in Calcutta and a free health checkup for hemophilia patients was organized.

Local hemophilia associations in seven **Italian** cities distributed information and organized fundraising events in the country's biggest ever bleeding disorders awareness campaign. The campaign generated significant national media coverage and was publicly supported by leading actors and a member of the Italian senate.

Milan's renowned opera house, La Scala, staged a performance of the ballet, *Giselle*, with proceeds going to hemophilia causes. Leading auction houses, Il Cigno and Christie's also organized auctions to raise funds for the hemophilia community.

Latvian patients and doctors held a well attended hemophilia information meeting in Riga as well as other events. Many of the activities focused on hepatitis prevention amongst people with hemophilia.

In **New Zealand**, a parliamentary dinner, organized by the national hemophilia association, was used as part of a compensation campaign for people with hemophilia who have contracted hepatitis C.

Special events in **Pakistan** were organized by hemophilia association chapters in Lahore, Karachi, Peshawar, and Quetta. Senior representatives of the national association appeared in a live television interview broadcast to 54 countries. The federal health minister presided over a gathering at the Pakistan Institute of Medical Science in Islamabad. Red Crescent officials, World Health Organization representatives, and other

Outdoor activities
in Argentina.



"Alejandro the Great"
from Venezuela.



Hemophilia association
members gather in Pakistan.

- A Global Celebration



Dhaka news conference.

dignitaries also attended the event, which attracted much media coverage.

The **Palestine** Avenir Foundation/ National Centre for Blood Diseases- Hippocrates celebrated World Hemophilia Day in Ramallah. Patients, families, and dignitaries gathered for a variety of events including presentations, laboratory tests, and children’s entertainment. Speakers urged patients to prevent hepatitis A and B through vaccination. Hemophilia association representatives used the opportunity to talk to the media about the need for improved hemophilia treatment and care.

The national hemophilia association in **Peru** celebrated World Hemophilia Day with various events, including a blood drive.

Members of **Portugal’s** hemophilia community, gathered in the historical city of Vila de Óbidos for an enjoyable day of events amongst the medieval buildings. The benefits of prophylaxis were promoted through posters distributed to hemophilia treatment centres and the association conducted a media campaign to raise public awareness of hemophilia.



A young girl with von Willebrand disease attends an event in Tegucigalpa.

The Hemophilia Association of **Uruguay** held its general assembly and organized a ceremony in memory of its former president, Douglas Piquinela, who died last year.

On April 17, Alejandro Garrido, became the world’s first person with hemophilia to compete in **Venezuela’s** Cruce a Nado Orinoco-Caroni, an international swimming race across the junction of the Orinoco and Caroni rivers. The 16-year-old student fought strong currents for 90 minutes to complete the 3.1 kilometre swim. He was greeted at the finish by his parents, doctors, and hemophilia patients.

To help national associations promote World Hemophilia Day, the WFH contacted media organizations and prepared posters, a fact sheet, and template news releases for the event. We are very pleased that many associations used this material and adopted the message about the importance of hepatitis A and B vaccination.

Thank you to all those who contributed to this report. Further World Hemophilia Day contributions will be posted on the WFH website: www.wfh.org. ■

World Hemophilia Day in Vila de Óbidos.



Hemophilia meeting in Ramallah.

Hemophilia information booth in Italy.



WFH regional update



AMERICAS

Argentina

The national hemophilia association has won its campaign for compensation to people with hemophilia and their families who were infected with HIV from contaminated blood products during 1979-85. The government has agreed to pay a benefit equivalent to about US \$200 a month to those affected.

The WFH helped the association to lobby the government successfully for US \$200,000 in funding to support hemophilia care activities and the purchase of treatment products. The grant represents an increase of US \$80,000 over previous years and will enable the association to maintain its activities. A WFH product donation of one million IU also means the association can continue to provide treatment to all people with hemophilia in Argentina.

Costa Rica and Honduras

Patient organizations have succeeded in lobbying both governments to pass laws guaranteeing that factor concentrates purchased by

the governments are licensed by the U.S. Food and Drug Administration or the European Medicines Evaluation Agency.

Ecuador

The national patient association has signed an agreement with the Lion's Club medical centre in Quito to provide care at minimal cost to people with hemophilia. The move reflects the Lion's Club mission of community commitment and will give hemophilic patients access to many medical facilities that were previously unavailable.

Mexico

A patient registry campaign has increased the number of people identified with hemophilia in 2004 from 2,344 to 2,974. A regional outreach program starts this year in Mexico City.

AFRICA

Lesotho and South Africa

Lesotho has established a new national patient group called the Lesotho Hemophilia Association. The WFH has approved a medical twinning partnership involving hemophilia treatment centres in Maseru and

Perth, Australia. During a visit last July, the WFH organized a multidisciplinary symposium with the Perth centre and South African volunteers.

WFH volunteer Kathy Mulder conducted physiotherapy training in Pretoria, South Africa, involving participants from different cities. Other patient education and skills training sessions were held in Pretoria and Johannesburg to enhance the national hemophilia association's outreach activities.

MIDDLE EAST

Bahrain

The WFH visited Bahrain for the first time, in February, and representatives met senior officials to discuss improvements in the country's hemophilia care. The delegation also met patients about starting a hemophilia association and joining the WFH.

Egypt

As part of the Global Alliance for Progress (GAP) in hemophilia agreement with Egypt, WFH volunteers conducted multidisciplinary, nurses, and musculoskeletal training sessions in March. The work-

shops, held in Cairo and Alexandria, were attended by almost 200 medical professionals, social workers, and patients.

Jordan

WFH president Mark Skinner visited Jordan in January to sign a GAP agreement with the ministry of health. WFH executive member Gordon Clarke conducted two patient education sessions in the capital, Amman, and the northern city of Irbid.

WFH volunteer Steve Kitchen held a training workshop in Amman last November for 26 laboratory scientists from different health facilities.

Lebanon

The WFH organized training sessions in December for patients, physiotherapists, and other rehabilitation experts. WFH volunteer Nichan Zourikian conducted the training for 17 physiotherapists and other rehabilitation experts.



Young hemophilia patient in Ecuador.



Rehabilitation training session in Lebanon.



Baku-Istanbul twinning partners.



Clinical seminar participants in Mongolia.

ASIA AND WESTERN PACIFIC

Bangladesh

The WFH visited Bangladesh for the first time and met with doctors, patients, and officials to discuss the country's hemophilia treatment and care needs.

China

The Guangzhou-Ottawa twinning partners organized China's 2nd Hemophilia Nursing Conference, in Guangzhou, with support from a WFH twinning grant. About 40 nurses and other medical professionals from across China attended the conference. The meeting established a national hemophilia nursing group that will respond to the urgent need to develop training and practice guidelines and standards. Presentations and workshops on hemophilia diagnosis and treatment were conducted by WFH volunteers from Canada: Dr. Koon Hung Luke, Dr. Man Chiu Poon, Diane Bissonnette, and Patricia Klein.

Indonesia

The WFH supported a hemophilia conference last September, which agreed to create the Indonesian Hemophilia Society. The new society unites both patients and doctors into a more

effective organization. Patients and doctors previously belonged to separate associations: the Indonesian Society of Hematology and Blood Transfusion, and the Indonesian Hemophilia Foundation.

Malaysia

Physiotherapy care for people with hemophilia was advanced in October by a treatment seminar and workshop attended by senior Malaysian officials and 87 medical professionals from hospitals throughout the country.

The training stressed the multidisciplinary team approach necessary for comprehensive hemophilia treatment. Both events involved WFH support and volunteers as well as the ministry of health, the Kuala Lumpur General Hospital, the National Blood Bank, and the Hemophilia Society of Malaysia.

The gatherings were followed by a three-day physiotherapy workshop led by WFH volunteer Piet De Kleijn, who shared his expertise on the guidelines, treatment protocols, and assessment of patients based, on international classifications. He also introduced specialized treatment methods for acute and chronic conditions faced by people with hemophilia.

Mongolia

In March, Mongolia's first clinical seminar on hemophilia and other bleeding disorders was held in Ulaanbaatar. Twenty-six physicians from around the country attended the seminar, funded by the WFH. The meeting was seen as important step towards improved hemophilia treatment in Mongolia.

Thailand

The WFH provided full or partial sponsorship for 25 physicians and patients from China, Laos, Myanmar, and the Philippines to attend last October's World Hemophilia Congress in Bangkok.

EUROPE

Azerbaijan

Azerbaijan and Turkey have set up a twinning partnership between treatment centres in Baku and Istanbul. The twinning will focus on improving laboratory diagnosis, staff training, educational material for patients and families, and establishing government supply of factor concentrates.

Belarus

A new hemophilia treatment centre is being set up in Minsk to provide adult and pediatric hemophilia care. The adult

centre is also starting a medical centre twinning with the hemophilia treatment centre in London, Canada. This constitutes a double twinning with Canada, since the Southwestern Ontario Region patient organization is also starting a partnership with its national counterpart in Belarus.

Macedonia

Home therapy is now more possible because the ministry of health is supplying 1.25 million IU of factor concentrates. The move follows years of lobbying by the national hemophilia association, with support from the WFH and other collaborators. The WFH is funding a computerized registry to plan, distribute, and monitor factor usage.

Russia

The federal ministry of health announced the welcome news in January that factor concentrates would be restored to the list of essential free-of-charge medicines. The ministry had withdrawn factor concentrates from the list in 2004. The move prompted an intensive lobbying campaign by the Russian Hemophilia Society and its chapters to protect the right of free access to replacement therapy by people with hemophilia. ■



Kathy Mulder (centre) conducts a physiotherapy training workshop in South Africa.

New Vice President Finance 'hits the ground running'

Richard Andrews
WFH Communications Officer

Australian CEO brings his international business experience to the WFH.

Rob Christie's teenage son, Scott, was diagnosed with mild hemophilia A as a toddler, after he cut his hand on broken glass. At the age of five, he contracted hepatitis C from tainted blood product. "Scott won the lottery after only four infusions," says his father grimly. "It's driven me to do all I can to help people with hemophilia."

Christie is the immediate past president of the Haemophilia Foundation South Australia (HFSA) and its current treasurer. He sits on a number of management committees for Australian hemophilia treatment centres and is the consumer representative for a coagulation user advisory group.

"My greatest achievement so far was to secure government agreement last year

to supply recombinant product to all people with hemophilia in Australia. I campaigned long and hard with the HFSA for that victory."

In addition to his background in hemophilia advocacy, Christie brings sound financial and business skills to his new position with the WFH. He has considerable experience in business management, sales, and marketing around the world and is the CEO of a major international corporation based in Hong Kong. "The combination of all that experience enabled me to hit the ground running when I became WFH Vice President Finance last October," he says.

"I'm impressed by the range and extent of the WFH's activities on such a lean budget. Because it has attracted so many skilled volunteers, the organization can do



Rob Christie,
the WFH's new
Vice President
Finance.

more work than much larger agencies. For example, the Global Alliance for Progress (GAP) in hemophilia project is outstanding and I'd like to see it expanded to support hemophilia treatment and care in more developing countries."

In addition to ensuring due diligence in WFH operations and sound financial management, Christie's vision is to increase and broaden the WFH's funding base. "The more successful the WFH becomes, the greater the demand for its services. The pharmaceutical companies have long provided valuable support but we should not rely on this sole source. I'm working to expand that support using my business background and relationships. I'd like to see other global corporations such as banks or insurance companies get involved with the WFH." ■

Jack's journey raises hemophilia and hepatitis C awareness

Richard Andrews
WFH Communications Officer

Young New Zealander overcomes the challenges of hemophilia and hepatitis C to achieve his goals.



Jack Finn takes a breather before facing another challenge.

Twenty-one-year-old Jack Finn set off last July on an epic 2,100 kilometre journey to travel the length of New Zealand by bicycle and kayak. The journey involved about six weeks in the saddle and Finn had to deal with bleeding joints, stomachaches, fatigue, driving rain, and bitter cold along the way. He also had to paddle across the notorious Cook Strait, which separates New Zealand's North Island and South Island.

"You hit walls, but you have to keep ploughing through them," said Finn, a member of Haemophilia Foundation New Zealand.

The aim of the journey was to raise public awareness of the compensation claims made by Finn and hundreds of other New Zealanders who contracted hepatitis C from contaminated blood products in the early 1990s. "Seventy per cent of people with hemophilia in New Zealand have hepatitis C because of inadequate screening tests," said Finn. The compensation is a

battle still to be won, but meanwhile Finn has scored other victories. He was recently the first person with hemophilia in New Zealand to graduate with a diploma in Outdoor Recreation Leadership.

Finn is currently pursuing further adventures in Australia, Europe, and the U.S.A. where he'll be encouraging members of other hemophilia organizations to follow their dreams and be active outdoors. His mother, Mary Hancock, who coordinated the New Zealand journey, says the biggest impact was to generate publicity about the effects of hemophilia and hepatitis C. "Jack's been a great model for New Zealand's hemophiliacs. He's a passionate and articulate young man. When he returns from overseas, his next project is to kayak around New Zealand in memory of his friends who died from AIDS because of infected blood." ■

New WFH Publications



Guidelines for the Management of Hemophilia

The WFH has developed a set of guidelines to ensure a basic level of hemophilia care. They include information on general management of hemophilia,

laboratory diagnosis, musculoskeletal complications, selection of clotting factor concentrates and other drugs, as well as protocols for the treatment of bleeding episodes. The publication also includes recommendations for plasma factor levels and the duration of replacement therapy for different types of bleeds, taking into account the economic resources of different countries.

Many countries that are starting to establish care do not have standard protocols to ensure that hemophilia is properly managed. Therefore, guidelines were developed by WFH volunteers Dr. Alok Srivastava, Dr. Paul Giangrande, Dr. Man Chiu Poon, Dr. Mary Chua, lab scientist Angus McCraw, and Dr. Jerome Wiedel. The guidelines are based on consensus guidelines used in Canada, India, Italy, South Africa, and the United States of America.

NMO Information Exchange

The WFH has launched an online discussion forum for National Member Organizations, creating a virtual meeting place for their leaders and key volunteers. Leaders can now visit one central site for the issues related to developing and sustaining a vibrant hemophilia society.

The information exchange includes presentations from the Global NMO Training (2004) in Thailand and a discussion forum where leaders can post

messages in English, French, or Spanish to share ideas, questions, concerns, and announcements with over 100 hemophilia associations worldwide. Most sections of the NMO Information Exchange are currently accessible only in English, but a Spanish version is under way.

Since it is a password-protected site, you must register and be approved by the national hemophilia organization in your country. To register, contact Louise Roy at lroy@wfh.org.

Passport 2005

The new edition of *Passport: Global Treatment Centre Directory* contains more than 900 treatment centres and national hemophilia organizations in over 100 countries. The directory contains postal, e-mail, and website addresses, as well as key contact people. The publication is a directory of hemophilia treaters worldwide and is a useful resource for people with hemophilia who are traveling to other countries. The new *Passport* will be available soon on www.wfh.org and in print.

WFH annual global survey

The WFH and its member organizations have continued to improve their global data collection efforts, increasing the number of people identified with bleeding disorders. Ninety-six member countries contributed data to the most recent version of the survey and 120,737 people with hemophilia were identified, an increase of seven per cent over the previous survey. The new survey also includes data on 43,334 people with von Willebrand disease and 13,584 people with other bleeding disorders. The WFH *Report on the 6th Annual Global Survey* will be released shortly.

Annual Report

The WFH *Annual Report* for 2004 will also be available soon on the WFH website.



Hemophilia in Pictures

The new edition of the WFH's most popular

publication is now available in print (English only). It provides basic information about hemophilia, home therapy, and assessing, preventing, and treating bleeds.

The publication consists of 40 durable binder pages sized 8 1/2 in x 11 in (28 cm x 22 cm) with a colour illustration on one side and text on the opposite side. You can also print your own copy for educational purposes from the website or order the CD-ROM.

Hemophilia in Pictures is currently available on the WFH website (www.wfh.org) in English, French, and Spanish. Arabic, Russian, and simplified Chinese versions are under way. Production of the CD-ROM containing all six languages has been delayed, but all orders will be filled as soon as possible. All National Member Organizations and hemophilia treatment centres will automatically receive one complimentary CD-ROM.

PRINT VERSION:

US\$50 for WFH members and US\$75 for non-members.
(Price does not include binder.)

CD-ROM:

US\$10 for WFH members and US\$20 for non-members.

WFH publications are available at www.wfh.org.

For print versions, contact Louise Roy at lroy@wfh.org. ■

'Donated factor saved my leg'

Richard Andrews
WFH Communications Officer

A founder of Bangladesh's hemophilia association survives the odds and now helps other patients.

Parimal Chandra Debnath remembers the day in December 2002 when a car hit the rickshaw carrying him home from work. The 32-year-old mathematician suffered a broken knee and complications from his severe hemophilia A threatened his future ability to walk and work. "The WFH provided an emergency supply of factor concentrate," says Debnath. "I could not walk. The donated factor saved my leg. The WFH also supplied emergency factor another time when I broke my shoulder in an accident."

Debnath grew up in a remote fishing village on the Bay of Bengal and had no access to treatment products before moving to Dhaka to study at university. "As a young boy, I went to hospital several times with severe bleeding. The only available treatment was the use of ice to relieve pain. I was lucky to live in a fishing village with ice factories, as ice is not available in many other parts of the country. I also remember taking lots of painkillers."

Debnath and his brother were born with hemophilia out of a family of four boys. Their schoolteacher father was determined that all four would complete their education, no matter what the odds. "I inherited that determination from my father," says Debnath.

"Although I often had to stay home, I still managed to finish school with good results."

He is now vice president of the Hemophilia Society of Bangladesh, an organization he helped form in 1994, with support from the late Ashok Verma, the guiding light of India's hemophilia movement. "People with hemophilia in Bangladesh were suffering," says Debnath. "We realized we had to do something.

"I could not walk. The donated factor saved my leg. The WFH also supplied emergency factor another time when I broke my shoulder in an accident."



Parimal Chandra Debnath,
from the Hemophilia Society
of Bangladesh.



Children and their families attend an information session organized by the Hemophilia Society of Bangladesh.



I went around collecting patients' names and contacted them to form an association. We started with just 11 patients and their families. Membership has grown since then to 300."

With a population of more than 130 million, many patients in Bangladesh remain undiagnosed. The association is planning to set up a hemophilia treatment centre in Dhaka as well as an education centre for children. "Most people with hemophilia come from remote areas and know little about the disorder. We need to reach out to them."

The high cost of treatment products makes them inaccessible to many people in Bangladesh. One infusion may cost the equivalent of a month's salary or more. Product supply is also a problem says Debnath.

"One of our members recently injured his eye and couldn't see. He was admitted to hospital but no factor was available. Luckily, the WFH was able to supply product within three days and now he can see again." ■

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WORLD FEDERATION OF
HEMOPHILIA 

Calendar of Events 2005

10th Congress of the European Hematology Association
2-5 JUNE 2005 – Stockholm
International Fairs, Sweden
Information: Eurocongres
Conference Management
Tel: +31 20 679 3411
Fax: +31 20 673 7306
eha2005@eurocongres.com
www.eurocongres.com/eha2005

Plasma Protein Forum 2005 (PPTA) 8-9 JUNE 2005 – Reston, Virginia
Tel.: +1 703-709-1234
www.pptaglobal.org/docs/ppforum05reg.pdf

European Conference on Rare Diseases (ECRD) 21-22 JUNE 2005 – Luxembourg
Tel: +31 20 512 3561
Fax: +31 20 512 3559
ipfa@sanquin.nl
www.rare-luxembourg2005.org

34th Annual Scientific Meeting of the International Society for Experimental Hematology 30 JULY TO 2 AUGUST 2005 – Glasgow, Scotland
Information: ISEH Registration
Tel: +1 202 367 1173
Fax: +1 202 367 2173
iseh@smithbucklin.com
www.iseh.org/meetings/2005.cfm

XX Congress of the International Society of Thrombosis & Haemostasis (ISTH) 6-12 AUGUST 2005 – Sydney, Australia
Tel.: +61 2 9241 1478
Fax: +61 2 9251 3552
isth2005@icmsaust.com.au
www.isth2005.com

WFH Musculoskeletal Congress 9-11 SEPTEMBER 2005 – Istanbul, Turkey
Information: Kathy Tsandilas, WFH Headquarters
Tel.: +1 (514) 875-7944
Fax: +1 (514) 875-8916
E-mail: ktsandilas@wfh.org

4th WFH Global Forum on the Safety and Supply of Hemophilia Treatment Products 26-27 SEPTEMBER 2005 – Montreal, Canada
Information: Kathy Tsandilas, WFH Headquarters
Tel.: +1 (514) 875-7944
Fax: +1 (514) 875-8916
ktsandilas@wfh.org

XXX World Congress of the International Society of Hematology (ISH) 28 SEPTEMBER - 2 OCTOBER 2005
Istanbul, Turkey
Tel.: +90 (312) 467 69 91
Fax: +90 (312) 467 70 62
alpers@serenas.com.tr
www.ish2005istanbul.org/

13th National Hemophilia Conference - Integrating Knowledge and Practice 30 SEPTEMBER - 2 OCTOBER 2005
Melbourne, Australia
Tel: +61 3 9885 7800
Fax: +61 3 9885 800
hfaust@haemophilia.org.au
www.haemophilia.org.au

International Course in Hemophilia - From Diagnosis to Therapy 10-14 OCTOBER 2005 – Malmö, Sweden

Tel.: +46-(0)46-222 07 53
niklas.parback@education.lu.se
www.medforsk.mas.lu.se/koag
(press 'Utbildning')

57th Annual Meeting of the National Hemophilia Forum Foundations 27-29 OCTOBER 2005 – San Diego, California, U.S.A.
Tel.: +1-800 424 2634, ext 4
meetings@hemophilia.org
www.hemophilia.org

Congreso Latino Americano Hemostasia y Trombosis 3-6 NOVEMBER 2005 – Viña del Mar, Chile
Tel.: +56-2-274-6714
congresolahtchile2005@terra.cl

46th Annual Meeting of the American Society of Hematology 3-6 DECEMBER 2005 – New Orleans, Louisiana, U.S.A.
Tel.: +1-202 776 0544
Fax: +1 202 776 0545
ash@hematology.org
www.hematology.org

Hemophilia 2006 World Congress 21-25 MAY 2006 – Vancouver, Canada
Information: Hemophilia 2006 Secretariat and Housing Bureau
Tel.: +1 (514) 394-2835
Fax: +1 (514) 875-8916
hemophilia2006@wfh.org
www.hemophilia2006.org

THANK YOU

Annual unrestricted contributions

These contributions support WFH activities to increase care worldwide for people with hemophilia and related bleeding disorders. The WFH is grateful to the following companies for their ongoing support.

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Biotest Pharma
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Specific sponsorship

Bayer – World Hemophilia Day
Novo Nordisk – Global hemophilia directory (*Passport*)
Wyeth – Twinning Program sponsorship

Global Alliance for Progress (GAP)

Baxter
Bayer
Jan Willem André de la Porte Family Foundation
ZLB Behring

Product donations

Baxter
Grifols
Wyeth
ZLB Behring

MUSCULOSKELETAL MEETING in Turkey offers advances in hemophilia treatment

Assad Haffar

WFH Program Coordinator Africa and Middle East

Rehabilitation experts discuss the latest treatment methods.

Orthopedic surgeons, physiotherapists, and other rehabilitation experts from around the world will meet in Istanbul, 9-11 September, for the WFH's 9th Musculoskeletal Congress. The meeting will enable participants to exchange ideas

and discuss advances in treatment, research, and methods of managing the musculoskeletal complications of hemophilia. This year's expanded program will include developments in joint treatments, such as radiosynovectomy.



Istanbul's magnificent St. Sophia is a major attraction for visitors.

WORLD FEDERATION OF HEMOPHILIA
RESEARCH - SUPPORT - EDUCATION
RESEARCH - SUPPORT - EDUCATION

The World Federation of Hemophilia's Fourth Global Forum

on the Safety and Supply of Treatments for Bleeding Disorders
Montreal, Canada - September 26 & 27, 2005

There is growing consensus in the bleeding disorders community that the supply and affordability of treatment products are as important as their safety. The theme for this year's forum is "Increasing the worldwide supply of safe, affordable factor replacement therapy." Experts from around the world will address the challenges of how to increase global access to treatment and how to expand supply without compromising safety.

Topics will include:

- The latest thinking on dosage
- The future of the clotting factor market for recombinant and plasma-derived products
- Plasma proteins to treat rare disorders
- Twin track pricing
- National tendering
- Regulatory harmonization
- An update on variant Creutzfeldt-jakob disease risk in plasma-derived products.

The Global Forum's 150 participants will come from around the world, including:

- Representatives of national and international regulators of blood products, including Federal Drug Administration, EMEA, and World Health Organization;
- National and international representatives of patient organizations, and other international organizations;
- Leading scientists, specialists, and clinicians in the field; and
- Representatives of the major blood fractionators and producers.

This biennial event provides a chance for stakeholders to hear from leading experts on hemophilia treatment products in an intensive and participatory setting. For all those with an interest in the safety and supply of plasma products and their analogs, anywhere in the world, the WFH Global Forum is of vital importance.

We hope you will join us in Montreal!

For more information and to register, please visit www.wfh.org.

Held every two years, the Musculoskeletal Congress attracts the top people in the field. Istanbul's central location will make attendance convenient for participants from many neighbouring countries in the Middle East, Eastern Europe, and Western Europe. This year's meeting immediately follows another congress in Istanbul, organized by the International Society of Orthopedic Surgery & Traumatology (SICOT). As a result, many medical specialists will be able to make the most of their trip to Turkey by attending both gatherings.

The venue itself is another attraction. Long described as "the bridge between East and West," Istanbul is a fascinating city with cultural richness, exotic bazaars, and the historical Sultanahmet area, home to tourist favorites like the Topkapi Palace and the Blue Mosque.

The WFH will follow up the success of a physiotherapy workshop held prior to the 2001 Musculoskeletal Congress in Lahore, Pakistan. Further pre-congress training sessions are being arranged this year with the University of Istanbul.

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