

Taking to the water in Kyrgyzstan

Catherine Hudon

WFH REGIONAL PROGRAMS MANAGER FOR EUROPE

The eagerness of the government of Kyrgyzstan, the medical community, and the Hematology Centre, the country's national member organization (NMO), has materialized into a promising start to improving hemophilia care and treatment in the country. Despite only joining the World Federation of Hemophilia (WFH) as an NMO in 2009, the Hematology Centre, located in the Kyrgyz capital of Bishkek, has already signed up for the WFH Twinning Program with the Mary M. Gooley Hemophilia Center in Rochester, New York, U.S.A.



A young participant in the hydrotherapy workshop.

The ambitious undertaking partners the two organizations with the goals of establishing accurate laboratory diagnosis of inherited bleeding disorders, developing and maintaining a national computerized patient registry, and promoting a comprehensive care

model while supporting a factor distribution and supply program in Kyrgyzstan.

As part of the development of a comprehensive care model, a hydrotherapy study was set up by the Rehabilitation Institute in Bishkek, with the assistance of their American twin, to demonstrate the great potential of hydrotherapy as part of a comprehensive care regime. Hydrotherapy, or physiotherapy in water, is a safe and effective way to introduce traditional physiotherapy to people with hemophilia in regions where factor is not available, because the resistance of the water minimizes weight bearing while strengthening muscles.

The seven children participating in the study had their initial range of motion documented and their progress will be monitored throughout the year. They participated in a 10-day hydrotherapy workshop before returning home to practice traditional physiotherapy with the WFH publication *Exercises for people with hemophilia*. Kyrgyz physiotherapist Ainura Abdyltaevna hopes the success of the study, to be completed in June 2012, may be used to demonstrate its importance to the Kyrgyz Ministry of Health, and eventually gain government support. ■

Keeping the advocacy momentum going

Amanda Bok

ADVOCACY PROGRAM COORDINATOR

Advocacy is an integral part of the work of our global bleeding disorders community, yet the demands of managing an effective advocacy campaign can become insurmountable when time and resources are scarce. For this reason, the World Federation of Hemophilia (WFH) is pleased to announce the launch of a grant program that will ease this constraint.

"We had heard from national member organizations (NMOs) that they had limited time or physical resources to manage their advocacy campaigns. Once their momentum was lost, it was hard to regain," said Gordon Clarke, chair of the Advocacy in Action working group of the WFH. "Our grant program is a new concept for the WFH and is an interesting and exciting aspect of advocacy initiatives within NMOs. The human support of an advisor, coupled with financial support and a dedicated staff member through the Advocacy in Action program can make the difference between a successful campaign and one that meanders over years with no clear results."

Launched in 2010 to build on previous advocacy initiatives, the Advocacy in Action program, comprises three main elements. It offers tailored training workshops on a thematic and inter-regional basis, provides grants and individualized coaching to selected workshop participants, and offers an advocacy recognition award to share best practices among the community. The grant portion of the program seeks to maintain the momentum from the workshops through to the successful completion of the advocacy objectives of NMOs.

Five grants, amounting to over US\$30,000, have been awarded so far to Latvia, Romania, Poland, Germany, and the U.K. For some recipients, progress is already becoming evident. "The Advocacy in Action grant program has given us access to ways of gathering data for our lobbying which we have never had access to before," said Dan Farthing, policy and communications manager for the UK Haemophilia Society.

Radoslaw Kaczmarek, an active volunteer with the Polish Hemophilia Society, was also enthusiastic about the opportunities the grant provides. "The WFH grant tremendously increases our chances of



Gordon Clarke, chair of the Advocacy in Action program.

success. It's hard to imagine a better way to make a difference in the hemophilia community." ■

All NMOs are eligible to participate in the Advocacy in Action program. For more information please contact Amanda Bok at abok@wfh.org.

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

NEWS FROM AROUND THE WORLD

WFH regional update



LEFT: Getting to know each other at a camp for adults in Costa Rica. RIGHT: Hemophilia treatment centre in Tashkent, Uzbekistan.

ASIA AND WESTERN PACIFIC

China

The Hemophilia Treatment Centre Network hosted the fourth East Asia Hemophilia Forum (EAHF) in June in Tianjin, with 280 people in attendance. The EAHF group, which was established in 2008, is comprised of Korea, Japan, China, and Taiwan. The Forum's goals are to provide a platform to drive scientific achievements and technical development, and to encourage academic activity and cooperation amongst its members, including co-research and exchange of education. The fourth National Pediatric Forum, which hosted over 50 pediatricians, was also held in Tianjin. The sixth National Physiotherapy Workshop took place in Wenzhou City and had 25 physiotherapists and doctors and 35 patients and families in attendance.

Thailand

The Thai Patient Club (TPC) held a two-day regional network leadership event in July for 60 participants from the eastern and southern TPC regional networks in Chonburi province. Strategic planning, communication and organization, the direction of the

TPC and its regional networks, and ideas of how to increase and recruit new volunteers were discussed.

Vietnam

The National Institute of Hematology and Blood Transfusion (NIHBT) organized a two-day National Hemophilia and Coagulation Congress in Binh Dinh province that over 300 doctors attended. The first day was mainly devoted to topics related to hemophilia. In addition, World Federation of Hemophilia (WFH) volunteers presented on national models of hemophilia care, comprehensive care, and the multidisciplinary care team. The new hemophilia treatment centre twinning between the NIHBT (Hanoi) and the Alfred Hospital (Melbourne, Australia), and the new hemophilia organization twinning between the Vietnam Society of Congenital Bleeding Disorders and the Irish Haemophilia Society will greatly assist the development of care in Vietnam.

EUROPE

Kazakhstan

During their May twinning assessment visit, the new Astana

hemophilia treatment centre (HTC) and its staff welcomed a representative from the National Research Hematology Centre of the Russian Academy of Medical Sciences who, along with a WFH delegation, met with the Deputy Minister of Health to discuss the importance of comprehensive care. The Astana HTC would like to create a national patient registry, improve laboratory diagnostics, train a multidisciplinary team, and educate patients.

Macedonia

Representatives from the Arizona, U.S.A. chapter of the National Hemophilia Foundation (NHF), conducted their twinning assessment visit to Macedonia in September. They met with current leaders of the Macedonian national member organization (NMO) as well as a group of patients and their families. The Skopje HTC, where outpatients are treated, and the hematology departments were visited. The goal of this twinning partnership would be to improve fundraising skills, develop membership, and improve organizational structure and communication.

Uzbekistan

The Russian Hemophilia Society conducted an assessment visit

in June for their second patient organization twinning as an established partner. Their vice-president visited colleagues from Tashkent, Uzbekistan, met the Deputy Minister of Health, and toured the Tashkent HTC. In addition, twinning was discussed with about 30 patients and their families with a delegate visiting from the Istanbul HTC that is twinned with the Tashkent HTC. The Tashkent organizational twinning would attempt to improve advocacy in order to raise public and government awareness, educate patients and their families, and increase membership through outreach activities.

AFRICA AND EASTERN MEDITERRANEAN

Algeria

The WFH, in cooperation with the Algerian Ministry of Health and the Algerian Hemophilia Association (AHA), organized a three-day laboratory diagnosis workshop in Algiers in May. The workshop focused on practical points related to lab diagnosis of hemophilia and VWD. During this visit discussions took place between the WFH, the AHA and the Algerian Deputy Minister

of Health to discuss the possibility of establishing a Global Alliance for Progress (GAP) project in Algeria in 2012. Following the meeting, a GAP development plan was drafted and sent to the Ministry of Health for comments and approval.

Jordan

Under the GAP agreement signed with the Jordanian Ministry of Health, the WFH organized a multidisciplinary symposium about hemophilia care in Amman. Participants compared their current situation, where discussion is focused on prophylaxis, to the country's situation before the GAP project in 2001, when the focus was on producing safe cryoprecipitate. The GAP visit included a trip to the new pediatric military hospital, which featured a presentation on prophylaxis use for children, and a half-day symposium on hemophilia in the northern city of Irbid.

Saudi Arabia

A WFH delegation visited King Saud University in Riyadh for a three-day hemophilia symposium, organized in part with the WFH. The Deputy Minister of Health confirmed that the Ministry of Health is now reviewing all procedures related to bleeding disorders care in the country and has appointed

a committee to review the current situation and provide feedback on areas where improvement is needed. This committee will suggest national treatment guidelines that will be adopted by the Ministry and used on a national level.

United Arab Emirates

The WFH organized two one-day nurses training workshops in the United Arab Emirates in April. The first training was at Tawam Hospital in the city of Al-Ain and the second was at Khalifa Medical Centre in Abu Dhabi.

VWD Outreach Project

The VWD Outreach Project, sponsored by LFB, has been completed in Lebanon, is currently underway in Egypt, and will commence in Mexico by the end of the year. The purpose of the project is to increase the diagnosis rate of VWD by proactively consulting patients. This is being achieved by distributing questionnaires, conducting interviews, and performing coagulation tests.

AMERICAS

Costa Rica

The Asociación Costarricense de Hemofilia (ASOHEMO) and the multidisciplinary team of the national reference centre for hemophilia in San José orga-



WFH Executive Committee member Dr. Magdy El-Ekiaby at a multi-disciplinary symposium in Amman.

nized a successful three-day camp featuring educational talks and sessions for adults. Participants ranged in age from 20-47 so that older patients could share their experiences and knowledge with younger participants. By the end of the camp participants agreed that they had forged important links with one another and developed a feeling of solidarity.

Dominican Republic

In September, the Fundación Apoyo al Hemofílico, in collaboration with the medical team from the Hospital Infantil Dr. Robert Reid Cabral, inaugurated a chapter in the northeastern zone of the country, with the ceremony taking place in the city of San Francisco de Macorís. There is a lot of enthusiasm and interest from the patients and health professionals in this region to start organizing with the national office to improve care for patients.

Ecuador

Two hematologists and a physiotherapist from the main reference hospitals in Quito made an evaluation visit to

the southern city of Cuenca in May. The purpose of the visit was to share information on comprehensive care, and the importance of rehabilitation. Many healthcare professionals and patients from this city, as well as the six surrounding communities, learned about treating and evaluating a person with hemophilia. Numerous evaluations were performed on patients to demonstrate techniques that could be incorporated into the practices of professionals in their own community.

Peru

The Asociación Peruana de Hemofilia, in conjunction with its medical committee, held a hemophilia workshop focusing on the importance of comprehensive care in the northern city of Chiclayo in September. Over 100 patients, family members, and healthcare professionals from around the country attended the workshop, which included topics such as the clinical aspects of treating hemophilia and sessions in dental care and nursing. ■



Patient evaluation in Cuenca, Ecuador.

WFH 2011 ANNUAL CAMPAIGN

Think about the first few years of a precious child's life...

...the first smiles, first teeth, first steps, first birthday, giggling and laughter—it makes you feel wonderful, doesn't it?

Now imagine this: Unending trips to a multitude of hospitals with your child crying inconsolably, recurring bleeding episodes that cannot be stopped for days or weeks, and your child suffering from joint pain that even painkillers can't control.

Then imagine **running out of money for treatment, tests, and travel to distant hospitals**, even after borrowing from every family member and *still* not knowing the cause of your child's suffering. Despite all of your love and effort, you wonder if you will drown under the tsunami of mounting fear, desperation, and heartache. Frightening isn't it?

Our work is not done. There are still an estimated **250,000+ people** in the world who have **undiagnosed and untreated** hemophilia, and millions more suffering from other types of inherited bleeding disorders with access to little or no treatment.

Monthly giving is a powerful way to make a difference. A modest recurring monthly donation of \$10 will add up to \$120 in a year! Donate online and choose the monthly donation option.

We count on your support.

PLEASE DONATE TODAY using the enclosed envelope or visit www.wfh.org.

THANK YOU.

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FEDERACIÓN MUNDIAL DE HEMOFILIA
Treatment for All



The journey of hope begins with YOU



Perspectives and debate at the Global Forum 2011

Mark Brooker

SENIOR PUBLIC POLICY OFFICER

Patient groups, pharmaceutical regulators, representatives from industry, not-for-profit fractionators, as well as doctors were in attendance at the World Federation of Hemophilia's (WFH) Seventh Global Forum on the Safety and Supply of Treatment Products for Bleeding Disorders in Montreal this past September.

This year's Global Forum focused on perspectives of risk, achieving a safe and affordable factor supply, and novel technologies. The session on perspectives of risk looked at the debate surrounding the exclusion of male blood donors who have ever had sex with another man. It also looked beyond that issue to the challenges for stakeholders in making decisions about the costs and benefits associated with the blood system as technology improves for both testing donations and inactivating pathogens. The debate surrounding achieving a safe and affordable factor supply focused on two issues that have previously been discussed at Global Forums and remain pertinent – health technology assessment (HTA) and inhibitors. Although vastly different issues, HTAs and inhibitors are both among the biggest threats patients face today. The high cost of hemophilia care means access to sufficient amounts of treatment products is a challenge in all economies, while the biggest danger from using clotting factor concentrates is the risk of developing inhibitors.

The novel technologies session offered an encouraging report on a new gene therapy trial for hemophilia B that is currently underway. The session also explored advances in technology to make safer cryoprecipitate – a technique that will be beneficial in countries where concentrates are not available in sufficient quantities. ■

The proceedings of the Seventh Global Forum will be published in early 2012. Presentations from the meeting are available at www.wfh.org.

Thank you to the sponsors of the Seventh Global Forum: Héma-Québec, the Ministère des Relations internationales du Québec, and the Ministère de la Santé et des Services sociaux du Québec.



Clowning around at the Kidlink conference.

All in the family

Declan Noone

IRISH HAEMOPHILIA SOCIETY

Family and the seemingly unending support they offer play an immensely important role in the life of a person with hemophilia. With this in mind, the Irish Haemophilia Society (IHS) has developed a series of programs to provide support and services to all members of the family, from infants to adults.

Three times every year, the IHS holds residential weekend conferences for approximately 50 children and up to 110 adults. Four separate age groups are catered to with conferences, educational events, and activities specifically designed and targeted to them over the course of a weekend. Adults might find themselves attending a debate; the Youth Group (12-18 years) features safe but challenging activities such as a clown school, drumming circle, or archery; Kidlink (7-11 years) includes group activities such as swimming and arts and crafts, in addition to educational elements that are introduced in a fun way through quizzes, and competitions. The Crèche group (0-6 years) introduces

hemophilia education through puppet shows, and last year used the World Federation of Hemophilia's (WFH) HemoAction website. This group is in such demand that the IHS is planning on dividing this program into two groups (0-3 and 3-6 years).

Meeting new people from early childhood increases children's self-esteem, enhances their personal growth, and reduces any sense of isolation they may feel by gently introducing hemophilia in an educational but fun environment. Total family involvement means that each family member benefits greatly from the interaction and contact with other families, which in turn builds community, spirit, and supports long-lasting friendships. "Other peoples' experiences help me look at the bigger picture and put my own experience of hemophilia in context," said Joan Buckley Keniry, the mother of a 10-year-old boy with severe hemophilia. "The children always enjoy the social aspect of the weekends immensely and it puts hemophilia in a very positive framework for those affected, as well as for their siblings and parents." ■

Closing the GAP in Jordan

Assad Haffar

DEPUTY PROGRAMS DIRECTOR AND
REGIONAL PROGRAM MANAGER FOR AFRICA
AND THE MIDDLE EAST

The Jordan Thalassaemia and Hemophilia Society is successfully closing the gap in health care after achieving the development goals set by the World Federation of Hemophilia's (WFH) Global Alliance for Progress (GAP) program.

After intensive efforts as part of the GAP project established in the country in 2005, and significant improvements in the care of people with bleeding disorders, Jordan's participation in the program has come to a successful end in 2011. "Hemophilia care in Jordan has seen exceptional improvement since the signing of the GAP agreement between the Ministry of Health in Jordan and the WFH. All people concerned by

hemophilia care in the country are feeling the positive impacts of this agreement," said Dr. Arafat Awajan, president of the Jordan Hemophilia Society.

With the cooperation of the Ministry of Health, an accurate national patient registry was established, which now counts 264 people with hemophilia, 31 people with VWD, and 66 people with rare bleeding disorders. Specialized training workshops were organized in different parts of the country, which strengthened the knowledge of members of the multidisciplinary team working in bleeding disorders care. In addition, two hemophilia clinics were established; one in the capital, Amman, and another in the northern city of Irbid. The Jordanian government confirmed its commitment to improving hemophilia care with the vast increase in the purchase of clotting factor concentrates. In 2005 the country purchased 500,000 international units (IUs), which soared to 4.5

million IUs in 2010, surpassing the original GAP target.

But perhaps the greatest impact was directly on patients and their families. "They saw GAP as a critical and very positive event that changed their lives and increased their hopes to live in better conditions," Dr. Awajan said. "Now they are able to receive the appropriate treatment when needed. They know more about their condition and are confident in the support they receive from the government and health professionals." ■

For more information about the GAP program, please visit www.wfh.org.

The WFH is grateful for the support of the GAP program by founding sponsor Baxter; sustaining sponsors the André de la Porte Family Foundation, Bayer, and CSL Behring; supporting sponsors Biogen Idec Hemophilia, Biotest, Talecris and Pfizer; contributing sponsor the Irish Haemophilia Society; and collaborating partner the World Health Organization (WHO).

Calendar of Events 2012

5th Annual Congress of the European Association for Haemophilia and Allied Disorders

22-24 February 2012 – Rome, Italy
Tel.: +39-02-5810-2846; +39-87167183
Fax: +39-02-9366-3665
Email: info@smc-media.com;
congress@smc-media.com
www.eahad2012.org

NHF Gene Therapy Workshop

2-3 March 2012 – Philadelphia, U.S.A.
National Hemophilia Foundation
Tel.: +1-212-328-3700
Fax: +1-212-328-3777
www.hemophilia.org

2nd CDC National Conference on Blood Disorders in Public Health

12-14 March 2012 – Atlanta, U.S.A.
U.S. Centre for Disease Control
Tel.: +1-404-320-1820
www.blooddisordersconferences.com

International Plasma Protein Congress 2012

13-14 March 2012 – Madrid, Spain
Tel.: +32-0-2-705-5811
Fax: +32-0-2-705-5820
Email: alexa@pptaglobal.org
www.ippc.net; www.pptaglobal.org

XXXIV World Congress of the International Society of Hematology (ISH)

25-28 April 2012 – Cancun, Mexico
Tel.: +52-55-55-24-11-12
Email: contacto@amehac.org
www.hematology2012.com/en/inicio.aspx

World Hemophilia Day 2012

17 April 2012
World Federation of Hemophilia
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CLAUDIA BLACK

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successfully plan our own congresses, and that each Congress could meet certain standards and mechanisms in terms of the programs, planning, and exhibit areas.

HW: Four years ago you became CEO of the WFH. How does this role differ from the 11 years you spent working specifically on programs?

CB: Well, it was quite a big difference for me and quite an amazing journey to do all this in one organization. My background is in international development and program work, so to move into a position where you are actually overseeing the entire organization is quite fascinating. This way you see all the pieces of the puzzle come together. When you work in programs you tend to only see life through programs. If you are a fundraiser, you only see things in terms of generating support. So you perhaps tend to see things in a more limited way. I consider it a real privilege to have worked with all of the departments as CEO. I thought I knew the WFH very well, but because I had not worked in-depth in the other departments, I did not really appreciate the complexity of what they did. Being the CEO put things in perspective. I think it broadened my understanding of the organization and the community.

HW: What are some of your favourite moments throughout your career at the WFH?

CB: There are many interesting experiences that I've had over the years that range from meeting wonderful people to visiting manufacturing plants where they produce treatment products for bleeding disorders. This is quite an eye-opening experience because you have to dress in plastic suits to visit the facilities. I have had many moving and exceptional moments arriving in countries where there was absolutely no care. I've felt the severe sense of desperation and the feeling of being totally overwhelmed – an "Oh my goodness" feeling. I felt that I just had to do something, and you don't know where to start.

HW: Are there any moments that especially had an impact on you?

CB: There was a time in Azerbaijan when I walked into a room and it was a whole group of mothers in tears. It was just after the fall of the Berlin wall, the collapse of the Soviet Union, and there was a desperate level of health care. These were mothers of boys with hemophilia that were so sick and



Dressed for a factory visit with Bruce Evatt (left) and Brian O'Mahony.

had absolutely no treatment whatsoever. Similar situations also happened in Georgia, Armenia, Russia, and China.

Another example, which was quite an amazing experience, was during the war in Lebanon just a few years back. There was a little Canadian boy who had VWD and he needed to be infused twice a week. He had gone to visit family in Lebanon when the war happened and they got stuck in the middle of the war zone. It was very scary because obviously they were going to run out of treatment product. The boy would have been lost to us; he was stuck there without help. So it is an amazing story that mobilized us all, including the boy's doctor in Canada who contacted the Canadian Hemophilia Society (CHS), who in turn contacted the WFH. The CHS and WFH worked with Canada's Ministry of Health and the Ministry of Foreign Affairs. Every day we were on the phone with the whole group just trying to coordinate how to make it work, because it was a question of days and hours for this boy. The team managed to get product from his treatment centre to a Canadian military base. From there it was brought in one of the military planes to Cyprus and then Lebanon where the Canadian military met with his family. Probably the scariest part for the family was making it to the meeting point with the Canadian army. In the end they made it safely and they were air-lifted out of Lebanon. Twenty-four hours later they landed in Canada safely.

HW: Looking ahead, what direction do you see the organization taking?

CB: Well definitely the big milestone coming up is the 50th anniversary of the WFH in 2013. I think that it is a very important event for the organization to celebrate its successes and what it has accomplished, but also to pave the way for the future. I think

the organization has become very strong in many different areas, whether it is better communications or expanded programs, strengthening patient organizations, or increasing the size of the Congress every year in terms of quality and attendance. Based on this, I think one point the organization needs to look at, in terms of its mandate, is other uncovered areas, such as research. I really believe that is where we can play a role that is useful for everybody in all countries. We have our global survey, which has been an amazing tool. The WFH can go a step further in terms of documenting results of treatment in different parts of the world, tracking the progress of patients, and their quality of life progression. These are things that could help everybody in the community and the WFH is capable of doing this. We can also play a role in setting standards and providing guidelines for treatment. I think it's important for the organization to cover the areas of research that no one else would be able to address. Beyond that, I think the WFH priority is sustaining what we are doing – continuing to do it as well or even better than ever.

HW: Is there a farewell message that you would like to convey to our readers?

CB: I just want the community to know they are outstanding people because they are very caring and committed to the patients and the families they serve. That, I think, is the strength of this organization. I will always remember and cherish the amazing people I have worked with worldwide, the ones who worked so hard to change things in their country. The WFH is there to provide tools, ideas, and guidance, but these people are the ones living with this on a daily basis and having to cope with the various hardships they have. I admire them greatly. It is just an amazing community, so they should be very proud of what they are doing and what they continue to do. ■

Thank You

In recognition of the organizations that have committed or contributed to the WFH's mission in 2011.

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Jan Willem André de la Porte

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Print Production

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Hemophilia World is published three
times a year by the World Federation
of Hemophilia (WFH).

Opinions expressed in *Hemophilia World*
do not necessarily reflect those of the
WFH. Permission to translate and/or
reprint all contents of *Hemophilia World*
is granted to interested hemophilia
organizations, with appropriate
acknowledgement of the WFH.

Esta publicación esta disponible
en español.

Cette publication est disponible
en français.

Hemophilia World is available as a PDF
file at www.wfh.org

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