

HEMOPHILIA WORLD

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www.wfh.org



Sharing Stories, Inspiring Lives

World Hemophilia Day 2011



Liane Cerminara
WFH COMMUNICATIONS MANAGER

What motivates people to strive to make a difference when the challenges they face seem insurmountable? What pushes them towards their goals? Find out at www.wfh.org/whd, where you can read profiles of remarkable people and post your own story on our "Share Your Story" forum.

In honour of all of the inspirational people who are part of the bleeding disorders community, from patients to health-care professionals, the World Federation of Hemophilia (WFH) is posting profiles on the World Hemophilia Day website. In addition to Marilyn Ness and Yuri Zhulyov, whose profiles are featured in this issue of *Hemophilia World*, you will meet a Mongolian

Be inspired, get involved
in Treatment for All

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



**Engaging
Individuals,
Empowering
Communities**

We all have a role in improving and protecting treatment for people with bleeding disorders. You can help by:

- Inspiring others by sharing your story
- Educating people about living with a bleeding disorder
- Getting involved with the bleeding disorders community at a local, national, or global level

WORLD HEMOPHILIA DAY | APRIL 17

To share your story visit www.wfh.org/whd



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WFH launches web-based HemoAction Games

Olympic athlete and a young woman who is a carrier, among others.

We also want to hear your story, so throughout the month of April we invite everyone in the bleeding disorders community to post their own experiences or a story of someone that inspires them on the World Hemophilia Day website. Everyone

who posts a story will have a chance to win a digital camera.

On World Hemophilia Day 2011 the WFH wants to engage people beyond the bleeding disorders community and raise awareness among them. Everyone

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Treatment for All





Dyeing the fountains red in Bucharest in 2010 was part of a successful campaign by the Romanian Hemophilia Society that resulted in health ministry approval of a 70 per cent increase in the hemophilia budget.

WORLD HEMOPHILIA DAY 2011

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is encouraged to talk about the importance of getting involved by sending an e-mail or text message to five friends who may not be familiar with bleeding disorders. Update your Facebook status with your plans for World Hemophilia Day and encourage friends to become fans of the WFH Facebook page. Another way to raise awareness beyond the community is to ask people at your workplace, school, or sports association to wear red on April 17.

Through our stories and successes, we have the power to bring about change. "Be Inspired, Get Involved in Treatment for All" this World Hemophilia Day and see how a

Through our stories and successes, we have the power to bring about change. "Be Inspired, Get Involved in Treatment for All" this World Hemophilia Day

small but dedicated community can create positive change around the world. ■

The WFH is grateful to Baxter, Bayer, Biogen Idec Hemophilia, Inspiration Biopharmaceuticals, and Novo Nordisk for providing funding to support World Hemophilia Day.

ABOUT WORLD HEMOPHILIA DAY

Every April 17 since 1989 the WFH has promoted World Hemophilia Day to increase awareness of hemophilia and other bleeding disorders. In 2011 the WFH is encouraging people to "Be Inspired, Get Involved in Treatment for All"; celebrating and supporting positive change for people with bleeding disorders and encouraging others to do the same. By working together towards a brighter future, we can achieve Treatment for All.

"When I was born with hemophilia, treatment didn't exist. My parents were told that it was doubtful that I would live into adulthood," said Mark Skinner, WFH president. "Today, someone born with hemophilia can lead a relatively normal life if they have access to proper treatment. Access to treatment is perhaps the biggest challenge facing the majority of people with hemophilia throughout the world. Only 25 per cent of those living with hemophilia are receiving adequate care. The WFH's vision is that one day treatment for all people with bleeding disorders will be available."

TELL US YOUR STORIES!

The WFH would like to hear how you and your organization or treatment centre celebrated World Hemophilia Day. Please send an update, along with a few high resolution photos to lcerninara@wfh.org by May 20.



HEMOPHILIA WORLD • APRIL 2011



Read inspirational profiles of individuals involved in the bleeding disorders community and share your story at www.wfh.org/whd

World Hemophilia Day 2010 activities in New Zealand (left) and China.

Improving Care— and Lives—in Russia

A Profile of Yuri Zhulyov, President of the Russian Hemophilia Society

Liane Cerminara

WFH COMMUNICATIONS MANAGER

As a child with severe hemophilia A, Yuri Zhulyov spent most of his time at home. Because of frequent bleeds and inadequate replacement therapy, physical activities like outdoor sports were not possible. He studied at home, where his school teachers would visit him, and later completed his law degree by correspondence. His experiences early in life encouraged him to fight for better care for others with bleeding disorders in Russia, and for over two decades he has dedicated countless hours as a volunteer to the cause.

Zhulyov helped found the Association for Persons with Hemophilia in Moscow in 1989, now called the Russian Hemophilia Society (RHS), and became president in 1993. “When we started many years ago, we didn’t have any treatment,” Zhulyov says. “The situation was really terrible. There were no products, no home treatment, and no prophylaxis.” Inspired by information he heard about factor concentrates that were available in other parts of the world, in 1999 Zhulyov arranged the first major national conference to discuss the dire situation of people living with hemophilia in Russia. “We had to fight for our lives,” he said. “Not only my life, but for the lives of my friends.” The conference was a success, resulting in the health minister purchasing small amounts of concentrates.

When Zhulyov began his work with the bleeding disorders community, the number of people living with hemophilia in Russia was unknown. There was very weak federal control, and coordination between local authorities and local hematology departments was virtually non-existent. Zhulyov guided the RHS to team up with the WFH’s Global Alliance for Progress (GAP) program in 2002, which is designed to close the gaps between the estimated number of people with hemophilia and those who are diag-

Inspired by information he heard about factor concentrates that were available in other parts of the world, in 1999 Zhulyov arranged the first major national conference to discuss the dire situation of people living with hemophilia in Russia.



Yuri Zhulyov

nosed and treated. After successfully creating a national public hemophilia registry in Russia, 7,629 people with hemophilia and other bleeding disorders are now registered in the country.

In 2005 Zhulyov led the RHS through an intensive lobbying campaign in parliament; after six months of hard work they were successful in adding hemophilia to a list of disorders which would receive part of the federal budget for treatment. Prior to the lobbying campaign, “in all of Russia there

were approximately 30 million units of factor VIII. Today we have 600 million units. Before there were 0.01 units per capita and now there are 4.17 units per capita. Before only in our dreams did we think about home treatment and prophylaxis treatment. Now all people who need it receive it,” Zhulyov says.

He credits his family for motivating him in his tireless work. “My family always strongly supported me in my efforts to improve hemophilia care. Feeling this support encouraged me and gave me the strength to move forward.”

Zhulyov was also aware of the lack of care outside of the large cities. During his tenure as president of the RHS, Zhulyov helped establish 63 regional chapters, and he continues to work non-stop to improve the availability of treatment and care not only in Russia but in other countries in the region. “Now we have access in Russia,” he says, “but unfortunately in other countries there have been no changes. I keep in mind my personal life and my personal history so that I am always motivated to help people with less.”

Zhulyov stresses that the next challenge is to keep the momentum. “In the beginning, people understood that we were fighting for our lives. Now that we have some established programs, people are relaxing. But if we stop our negotiation with authorities, if we stop our support for patients and physicians, very soon it will not be progress but regress.” ■

The WFH is featuring profiles of inspirational individuals on its website in the lead-up to World Hemophilia Day on April 17. Visit www.wfh.org/whd to read more profiles and to share your story with the international bleeding disorders community.

For further information about the WFH GAP program please consult the Programs tab at www.wfh.org.

A Friend's Message to the World

A Profile of Filmmaker Marilyn Ness

Liane Cerminara

WFH COMMUNICATIONS MANAGER

Marilyn Ness was dumbfounded when her childhood friend, Mathew Kleiner, recounted the experience of how he and others with hemophilia had been the unknowing victims of a massive failure to protect the blood supply, or as he described it, the "perfect storm of failure," that was responsible for affecting the rest of his life. As a young man in the early 1980s, he was one of 10,000 people with hemophilia in the United States of America who contracted HIV, in addition to 15,000 who contracted hepatitis C due to the mass contamination of factor concentrate products that had been approved by the U.S. Federal Drug Administration. "How could I have been conscious and living and breathing while all of this was going on and not know about it?" asked Ness. The next question she asked

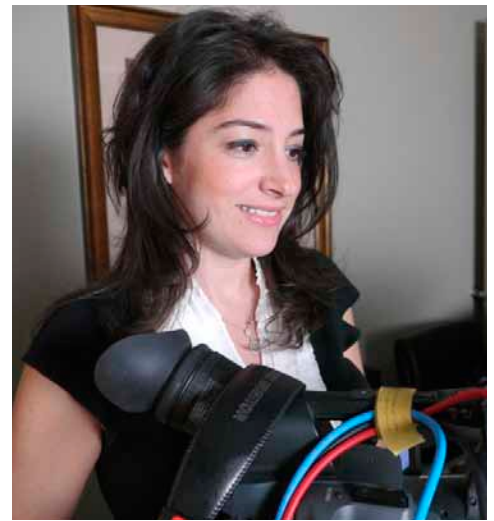
Today, over 60 per cent of the plasma used globally for fractionation comes from the U.S.A., therefore reverberations can be felt around the world.

Maintaining a safe stock of blood and safety procedures in the U.S.A. directly affects everyone's interests.

herself was why others shouldn't know about it too.

Motivated by her friend's claim that there had never been any decent answers provided about the tragedy, and compelled by his harrowing experience, Ness was driven to share the story with the world. Her approach of recounting this tragedy from the perspective of those who lived through it, from families and medical professionals to drug companies and government regulators, her account of the resulting effects on people with hemophilia, and in turn the birth of advocacy in the hemophilia community, takes the form of a feature-length documentary entitled *Bad Blood: A Cautionary Tale*, which premiered in New York City on July 28, 2010. Its message that "your voice can make a difference" clearly resounds throughout.

Without prior knowledge of hemophilia, Ness encountered some bumps along the way. But when she got discouraged she didn't have to look any further than the bleeding disorders community for motivation. She was inspired by the "tiny community [20,000 in the U.S.] that has made a huge impact." She recalled the people battling three diseases (hemophilia, hepatitis C, and HIV) who continued to march on despite their many challenges. In fact, this "tiny community" of patients and their friends and families managed to change the



Marilyn Ness promoting her film *Bad Blood*.

way treatment products are collected, processed, and approved in the U.S.A.

Although the film tells an American story, the topic is relevant to a global audience. Today, over 60 per cent of the plasma used globally for fractionation comes from the U.S.A., therefore reverberations can be felt around the world. Maintaining a safe stock of blood and safety procedures in the U.S.A. directly affects everyone's interests. Ness promotes the film as a valuable advocacy tool because it demonstrates the need for a regulatory authority that is strong enough to stand up to corporate entities. She says that if people could carry one message away from the film, she hopes that it would be "when you grow your voice you grow your strength."

The film has been screened numerous times since its opening night and a shorter version of the film will be broadcast on PBS in the U.S.A. in 2011 (dates to be confirmed). It is currently being distributed in libraries and universities and Ness is looking into possibilities for foreign broadcast. Government agencies and pharmaceutical manufacturers have been using *Bad Blood* to train new employees in order to maintain an institutional memory. Ness' ultimate hope is that "this story has the power to change a system at risk for repeat failure. It's time it was remembered." ■

Visit www.wfh.org/whd to read more profiles and to share your story with the international bleeding disorders community.

Personal and institutional DVD versions of *Bad Blood* are available for purchase at www.badblooddocumentary.com.



Enhancing Affordability and Global Supply

Are Biosimilars a Solution?

Mark W. Skinner
WFH PRESIDENT

Biosimilars, also known as follow-on biologics, are widely touted as a key ingredient to improving affordable access to biologic products, such as clotting factor concentrates. Historically, generic versions of chemical drugs, identical in safety, purity and effectiveness, have improved affordability compared to their brand-name drug counterparts. Manufacturers of generic drugs can market these products once the period of patent protection for the brand-name drug ends. A hot public policy topic is whether and how best comparable results can be achieved for biologics derived from living organisms as has been achieved through generic versions of chemical drugs.

In an era of government budget deficits and escalating healthcare costs, lower prices for biologics could greatly benefit both patients and those who are responsible for paying for them. With 75 per cent of the world's population having limited or no access to treatment, pursuing strategies to improve access is an important objective.

The cost savings resulting from the use of generic drugs is due to many factors, including the utilization of streamlined product development and regulatory requirements, such as reducing or eliminating requirements for clinical trials. Whether a streamlined regulatory approval process is appropriate for complex biologics is a central issue facing regulators today. While we would all welcome the arrival of new lower cost treatment, we should not be willing to accept an expedited regulatory approval process that places patient health and safety at risk.

Perhaps one answer to the debate is in the name used to describe the new product itself. The term biosimilars is used because the final product is fundamentally similar, but not identical, to the original. The complexity of large-molecule biological therapies and the intricacies of the manufacturing process make it impossible to exactly repli-

Today, the risk of inhibitor development has replaced pathogen risk as the most significant adverse event facing patients with severe hemophilia A

cate a product. Unfortunately, even minute changes could have dramatic consequences for patients.

Today, the risk of inhibitor development has replaced pathogen risk as the most significant adverse event facing patients with severe hemophilia A. Quality of life for someone with an inhibitor is greatly reduced; treatment involves significantly higher costs and more intensive treatment regimens. It is vitally important to include an assessment of immunogenicity for biosimilar products, which is best achieved through appropriately designed clinical trials.

Clinical trials are essential in the regulatory approval process to ensure that biosimilars are safe and effective, including meeting an appropriate standard of immunogenicity. Skipping this important step could result in patients receiving treatment without adequate understanding of a product's effect and potential adverse events. Rightly, in their guideline for biosimilars, the European Medicines Agency has insisted that plasma protein products and their recombinant alternatives must have the equivalent clinical dossier as the original innovator products.

Allowing a biosimilar to forgo human clinical trials makes it impossible to accurately claim that the follow-on product will have the same effectiveness and absence of immunogenic response as the reference product. This shortcut could result in therapies that promise to be effective, but are actually harmful to the patient.



Ensuring the development of safe, effective, and therapeutically equivalent biological products at a lower cost is a laudable goal, but it should not be achieved in a manner that risks the health and safety of patients. Biosimilars should be required to meet current safety and efficacy requirements with appropriate clinical studies that will ensure that the similarity of the biosimilar product in the laboratory with the innovator product is matched with acceptable responses in patients receiving the product. Until assurances can be made that patients will not respond adversely, any abbreviated regulatory approval process should take these issues into consideration and require follow-on biologics to demonstrate equivalent safety, quality, and efficacy. ■

Von Willebrand Disease... A Modern Pilgrimage

Alison Street, MD

WFH VICE-PRESIDENT MEDICAL

The World Federation of Hemophilia (WFH) will be celebrating its 50th anniversary in 2013, and is planning a two-year celebration kicking off at the WFH 2012 World Congress in Paris, France. As we embrace the future, we remember lessons from our past, how they were learned, and who taught them to us.

It has been 85 years since professor Erik Adolf von Willebrand, an esteemed Finnish physician who practised in Helsinki, reported the case of a young girl, Hjördis, who was taken to see him during her summer vacation by her schoolteacher from Föglö, one of the Åland Islands which are situated between Sweden and the Finnish mainland.

Hjördis had a serious bleeding problem from which some of her siblings and other family members also suffered, and indeed had died. The schoolteacher, together with the girl's mother, provided details of related family members and their bleeding symptoms, which were carefully recorded and analysed by professor von Willebrand in this landmark paper on hereditary bleeding disorders.

He recognized the differences from classic hemophilia with its clinical features of joint and muscle bleeding, clear X-linked transmission, with only exceedingly rare expression in females, as well as from the descriptions of a variety of inherited and acquired platelet disorders. He thought that the disease he was reporting, now known to us as von Willebrand disease (VWD), was also inherited through X chromosome mutations, which we now know not to be the case. His other comments are made with careful description and thoughtful reflection in his recognition that this was a previously unclassified hereditary bleeding disorder. As the paper was published in Swedish it may not have had the immediate impact it deserved.

Hjördis died at the age of 14 in the middle of a severe winter, during her fourth

It has been 85 years since professor Erik Adolf von Willebrand, an esteemed Finnish physician who practised in Helsinki, reported the case of a young girl, Hjördis, who was taken to see him during her summer vacation by her schoolteacher from Föglö

menstrual period. There was no diagnostic testing, blood transfusion, or other support available at that time to save her or many of her family members whose shortened lives are recorded on the headstones in Föglö's graveyard.

Professor Inga Marie Nilsson from Malmö and professor Margareta Blombäck from Stockholm visited the Åland Islands in the 1950s to further study and treat members of Hjördis family by developing accurate diagnostic tests and trialling effective therapies. They are two of the many famous hematologists whose careers have at least partially revolved around unravelling the complexities of the scientific and clinical aspects of von Willebrand factor and VWD—and there remains much to be learned.

In September 2010 I was privileged to be invited as a representative of the WFH to the clinical and scientific faculty of a meeting held in Finland (convened and chaired by Professor Erik Berntorp from Malmö) to discuss contemporary issues and future challenges in the understanding, diagnosis, classification, and treatment of VWD.

The quality of the scientific presentations and the interactive discussions were spectacular and the proceedings, when published, will be highly cited; sufficient reason indeed to judge this meeting to have been very successful. Rarely however, do meetings have such an emotional impact.



We were so privileged to have professor Blombäck as a participant; a “national living treasure” whose obvious skill, dedication, and passion for her work was quite inspirational to all of us as she related her story of the original VWD family. In recounting his famous ancestor's medical curriculum vitae, professor von Willebrand's great-grandson, a geriatrician from Helsinki, brought to life (with our greatest admiration for his prodigious output and energy!) the man whose name is so well known to us. And most importantly, standing at the graveside of 14-year-old Hjördis, we realized that wherever we live in the world, it is important to learn, teach, and work together to achieve Treatment for All. ■

Forging a Spirit of Solidarity

Senegal and France undertake a Twinning partnership

Thomas Sannié

PRESIDENT OF THE FRENCH HEMOPHILIA ASSOCIATION AND WFH EXECUTIVE COMMITTEE MEMBER

When participating in a World Federation of Hemophilia (WFH) Twinning partnership, it goes without saying that you want to achieve your very best, but in order to be successful, good intentions have to be paired with dedication to teamwork and a strong sense of belonging to a community working towards a common goal.

In October 2009, the Ile de France chapter of the French Hemophilia Association (*l'Association française des hémophiles – Ile de France*) sent a letter to the Senegalese Hemophilia Association (*Association Sénégalaise des hémophiles*) to initiate a Twinning relationship. The following summer, the Hemophilia World Congress in Buenos Aires provided the opportunity to discuss the possibilities of working on a communal project with its president, Mohamed Yassine.

Pairing up for a Twinning project felt natural thanks to our countries' shared history, culture, and language. A hemophilia treatment centre partnership that had been formed a year earlier between Dr. Chantal Rothschild of the Necker Hemophilia Treatment Centre (HTC) in Paris (*Centre de Traitement de l'Hémophilie de Necker à Paris*) and Dr. Saliou Diop of the National Blood Transfusion Centre in Dakar, Senegal (*Centre National de Transfusion Sanguine de Dakar*) further solidified the relationship.

We worked together over the summer to prepare for our first trip to Senegal in



Thomas Sannié (left) and Mohamed Yassine enjoying each other's company at the Senegalese Hemophilia Association office.

October 2010, and to establish a three-year action plan that would run to the end of 2013. The objective of this initial visit was to see first-hand how we could assist the Senegalese Association. Edouard Hamelin, treasurer of the Ile de France chapter, and I left France confident but not knowing quite what to expect, and excited to see what was awaiting us.

When we arrived in Dakar the heat hit us like a tonne of bricks. We had decided to stay with a native of Dakar who welcomed us for our five-day visit; living in a central neighbourhood of the city meant we were in the middle of all of the action and we were able to get a real feel for the place. All the meetings we had and the people we met during this whirlwind visit served to strengthen our desire to make our partnership with Senegal a success by helping to

improve the lives of Senegalese people living with bleeding disorders.

In five days we met a lot of people, including doctors, physiotherapists, and patients, as well as members of the Senegalese Hemophilia Association and the National Blood Transfusion Centre. We combed through the details of the three-year Twinning partnership and identified where we would need to invest our common energies, and reviewed our respective strengths and weaknesses to get to know ourselves and each other better. This time together forged bonds of friendship, an element that will be necessary in keeping up our energy over the next three years.

Both organizations were enthusiastic; this partnership is an adventure that awaits us, that will lead to concrete improvements in the lives of people with hemophilia in Senegal. This improvement will not only be noticeable in patient associations but in the daily lives of children, men, and women who, thanks to our combined work, will live better lives in the coming years. They will be able to go to school, find a job, and live in the heart of their community with dignity.

This adventure is also a wake-up call for people with bleeding disorders in France. It is a reminder that not too far away men and women with bleeding disorders have to courageously fight for their lives. This struggle can teach us a lot about what we should appreciate at home and that this is a battle that deserves support.

This partnership will be based not only on support through capacity building activities but emotional and motivational support between people with bleeding disorders in Senegal and France. This will forge a spirit of solidarity between the two communities, and we will take the time needed to develop our relationship and let it grow. ■

The WFH Twinning program links emerging and established hemophilia treatment centres and organizations to improve treatment and care for people with bleeding disorders around the world. To read more about WFH Twinning programs please visit www.wfh.org and click on the Programs tab.

The WFH is grateful for the exclusive support provided by Pfizer for the WFH Twinning program.



Meeting with the National Blood Transfusion Centre in Dakar, Senegal.



Participants at the nurses' workshop in Belgrade, Serbia.

Comprehensive Care Model Highlighted at Serbian Nurses' Training Workshop

James Munn

WFH NURSES COMMITTEE VICE-CHAIR

Based on an integrative public health model, comprehensive care in hemophilia began in the U.K. in the 1940s. This model of care has been successfully integrated into hemophilia treatment centres (HTCs) around the world ever since. Improvement in patient health outcomes and reduction in healthcare resources have been documented when this approach to care is utilized. The success of the model has been so profound it is now recommended by the World Federation of Hemophilia (WFH) and the World Health Organization (WHO), and the WFH provides workshops for care providers around the world on the approach.

Last November, a nurses' workshop organized by the WFH and the Serbian Hemophilia Society was conducted in Belgrade, Serbia, highlighting the nursing role in comprehensive care. Most important to the success of this two-day workshop

was the participation and support of the regional HTCs. In attendance were nurses, hematologists, blood bank administrators, foundation representatives, a social worker, and several people with bleeding disorders. Individuals came from treatment centres in Serbia, Macedonia, Croatia, and Bosnia and Herzegovina. The audience itself was a wonderful cross-section of comprehensive care providers, and the participation from the host country was amazing. Lijljana Rakic, a nurse from the adult treatment centre, and Bojana Zindovic, a nurse from the pediatric hospital, gave presentations at the training session. Rakic presented the "Hemophilia 101" lecture while Zindovic gave a personal account of her experience as a WFH International Hemophilia Treatment Centre fellow working with the Serbian HTC's twin in Hamilton, Canada.

The workshop was an interactive experience with several half-day training sessions, including one titled "Case Studies" provided by members of the audience, where it was evident that comprehensive care was

During discussions at the meeting it was evident that access to resources in Serbia and the surrounding area are not at the same level as Western Europe, but the passion for providing great care to patients using a comprehensive model was unparalleled.

paramount to success. The dedication each audience member brought to the workshop and the willingness to share experiences and educational materials with one another was crucial to the course's effectiveness. This workshop could easily spearhead the development of a national or regional nursing committee dedicated to the care of people with bleeding disorders.

During discussions at the meeting it was evident that access to resources in Serbia and the surrounding area are not at the same level as Western Europe, but the passion for providing great care to patients using a comprehensive model was unparalleled. The message was clear: comprehensive care will flourish in this part of Eastern Europe and the patients from this region will be the ultimate beneficiaries of this service. ■

Closing the GAP in Moldova and South Africa

Antonio José Almeida
WFH PROGRAMS DIRECTOR

South Africa and Moldova have been chosen to join the World Federation of Hemophilia's (WFH) Global Alliance for Progress (GAP) program in 2011 for their strong medical and volunteer cooperation, and commitment to improving care for people with bleeding disorders. GAP is a ten-year healthcare development project launched in 2003, designed to increase the diagnosis and treatment of people with bleeding disorders globally.

BUILDING INFRASTRUCTURE IN SOUTH AFRICA

South Africa has a population of over 49 million and an estimated 3,280 people with hemophilia. The South Africa Haemophilia Foundation (SAHF) was formed in 1970 and became an accredited member of the WFH in the same year. A national hemophilia program was officially recognized in 2000.

One of the major goals of the GAP program here is to help restore the infrastructure for hemophilia care to effectively implement the national hemophilia program and stimulate the Department of Health to invest more in care at the provincial and national levels, in addition to addressing the need of effectively treating complications, such as inhibitors. The program aims to diagnose 500 people with hemophilia, increase the number of people diagnosed with von Willebrand disease, and integrate the national hemophilia registry into the government's chronic disease registry. Another objective is to support and strengthen the SAHF's outreach activities.

Learning about the diagnosis of hemophilia in Moldova.

IMPROVING DIAGNOSIS AND CARE IN MOLDOVA

Formerly part of the USSR, Moldova is a very small European country with a population of just over 3.6 million and an estimated 195 people with hemophilia.

The Moldovan Public Society of Hemophilia became an associate member of the WFH in 2004 and a fully accredited member in 2008. The Ministry of Health has been supportive of changes and improvements for people with bleeding disorders. The hemophilia treatment centres in the capital, Chisinau, have started assembling multidisciplinary teams, and the Ministry of Health recently started supplying minimum amounts of clotting factor concentrates; 0.13 International Units of factor VIII concentrates per capita in 2010.

Despite these accomplishments, improvements need to be made to diagnostic capacity and to the care system. There is currently no national registry, treatment protocols are not implemented throughout the country, treatment centres need to be established in the regions, and funding for reagents and factor concentrates remains uncertain. As GAP progresses we hope to see improvements in these areas. ■

To read more about GAP click on the Programs tab at 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 and CSL Behring; supporting sponsors Bayer, Biogen Idec Hemophilia, Biotest, Talecris and Pfizer; contributing sponsor the Irish Haemophilia Society; and collaborating partner the World Health Organization (WHO).



President Carlos Gaetan Fitch (left), and secretary Martha Monteros (right) of the Federación de Hemofilia de la República Mexicana with the National Commissioner of Social Protection for Health in Mexico.

Mexico to Fund Treatment for Children with Hemophilia

Luisa Durante
WFH REGIONAL PROGRAM MANAGER,
LATIN AMERICA

In January, Mexican president Felipe Calderón announced that treatment for children with hemophilia and von Willebrand disease without social security will be financed by the Seguro Popular, the Mexican social health protection scheme. Beginning this year, approximately 200 children who do not have social security will receive treatment and have access to comprehensive care until they are 10 years old. This means that there will be a new generation of people with these disorders in Mexico that will have adequate, appropriate and preventative care from birth, resulting in a better quality of life.

"We are on the right path. After several years of advocating for better care with the Seguro Popular, the government of Mexico has understood the reasons for treating hemophilia properly and decided to invest in comprehensive care. Our hope is that the hospitals that will be providing the treatment will begin doing so this year and that the children will be able to receive adequate care," said the president of the Federación de Hemofilia de la República Mexicana, Carlos Gaetan Fitch. ■



Moving Forward with Advocacy in a Challenging Economic Environment

Antonio José Almeida
WFH PROGRAMS DIRECTOR

Patient representatives from eight national member organizations (NMOs) in Western and Central Europe gathered in London, U.K., last December for a tailored advocacy training workshop, "Data Collection and Use in a Challenging Economic Environment." This was the first in a series of 12 workshops that will be conducted over a five-year period as part of the World Federation of Hemophilia's (WFH) new Advocacy in Action program. The program was established to provide training and assistance to NMOs for advocacy projects and activities.

Participants discussed the importance of analysis, accurate data collection, and built a case to pursue their efforts towards optimized health planning and treatment. Looking at health economics, they explored



Participants at the Advocacy in Action training in London.

strategies on how to maintain standards of care, and protect care from the potentially damaging impacts of the global economic recession and recent threats to national funding for bleeding disorders.

According to Dan Farthing of the UK Haemophilia Society, the skills, knowledge, and tools learned during the workshop "helped focus our minds and gave us a way of stepping back from our advocacy work and to think more strategically."

Participants left the workshop armed with individual advocacy strategy plans to present and finalize with their patient organizations. NMOs will have the opportunity to submit their finalized plans to the WFH for possible grants and individualized coaching support through the Advocacy in Action program. ■

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

Training Lab Trainers for Future Success

Aislin Ryan
WFH PROGRAM OFFICER

Last November, eight laboratory professionals from around the world travelled to the U.K. to participate in the World Federation of Hemophilia's (WFH) fourth Training the Trainers Workshop on Laboratory Diagnosis, held at the Katharine Dormandy Haemophilia Centre and Thrombosis Unit at the Royal Free Hospital, London. Steve Kitchen and Angus McCraw, present and past chairs of the WFH's Laboratory Sciences Committee organized the workshop in collaboration with Sarah Brooks, Anne Riddell, and other colleagues from the centre. The five-day training course included both lectures and practical demonstrations in the laboratory.

This is the first time the WFH has collaborated with the International Society



Training the Trainers with practical laboratory demonstrations.

of Thrombosis and Haemostasis (ISTH) to broaden the scope of the workshop to include the diagnosis of thrombotic and hemostatic disorders. Ton van den Besselaar (Netherlands), Guido Reber (Switzerland), and Peter Cooper (U.K.) attended on behalf of the ISTH to present on the diagnosis of various thrombotic disorders. Topics covered under hemostasis included factor assays, laboratory investigation of inhibitors, von Willebrand factor testing, genetic aspects of hemophilia, and internal and external quality control.

Training the Trainers workshops have a dual purpose. As with all WFH training workshops, they serve to improve knowledge by providing detailed information on various aspects of the diagnosis of bleeding disorders. At the same time, they supply the tools and information required to organize laboratory diagnosis workshops

in participants' own countries and regions. It was clear from feedback that attendees were pleased to meet and learn from experts in the field as well as interact with counterparts from around the world. Daniella Dazzi from Brazil noted, "I enjoyed the training a lot because it gave me the opportunity to exchange experiences with others and learn more about coagulation."

Participants took home presentations and other training materials to use in their own local training initiatives, including the newly published *Diagnosis of Hemophilia and Other Bleeding Disorders: A Laboratory Manual*, which will serve as an important reference guide in each of their laboratories. ■

Diagnosis of Hemophilia and Other Bleeding Disorders: A Laboratory Manual is available to download or order from www.wfh.org.

Launch of “Me and My Genes”

An Interactive Video for Young Carriers of Hemophilia A or B

Patricia Stewart

CANADIAN HEMOPHILIA SOCIETY VOLUNTEER

The Canadian Hemophilia Society (CHS) has created an interactive video to provide pre-teen and teenage carriers and possible carriers of hemophilia A or B with age-appropriate information about what it means to be a carrier.

“Me and My Genes” features a young girl working through a series of questions and answers to learn about inheritance, carrier testing, and how to manage bleeding symptoms, as well as personal or social situations carriers may encounter in their teens. The video also includes interactive buttons for viewers to access tips about dealing with possible problems, myths about hemophilia, fun facts for young carriers, and links to relevant websites. Viewers can test their knowledge about what they’ve just learned through an inter-

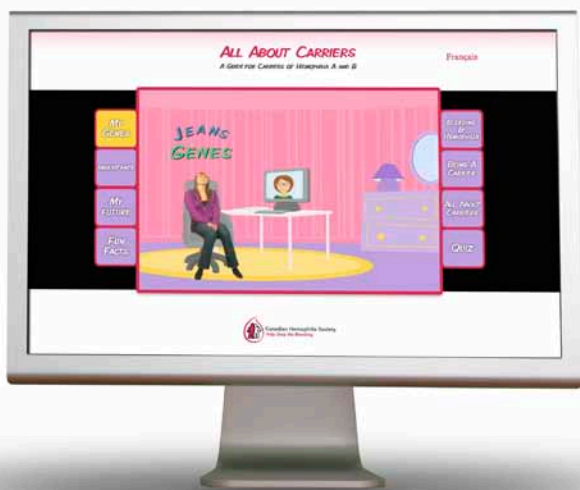
FUN FACTS FROM “ME AND MY GENES”

- Hemophilia is sometimes called the ‘royal disease’ because Queen Victoria, who ruled England from 1837–1901, was a carrier.
- Queen Victoria’s great grandson had hemophilia, and a local monk was the only one able to relieve his pain—using hypnosis!
- Hemophilia occurs naturally in dogs and is inherited in the same way it is with humans.

active quiz with written and visual multiple choice answers. There’s only one chance to get the right answer, and the tally at the end of the quiz tells participants how they have done.

It is hoped that “Me and My Genes” will provide young girls who may have inherited the hemophilia A or B gene with information to deal with the impact this disorder can have on a young carrier’s quality of life and health. ■

Me and My Genes is available for viewing on the CHS website in both English and French at www.hemophilia.ca/genes/.



Let the Games Begin!

WFH Launches Web-Based HemoAction Games

Jennifer Laliberté

WFH EDUCATIONAL MATERIALS MANAGER

Children around the world can now learn about hemophilia in the language they know best: play! The World Federation of Hemophilia (WFH) has recently launched the HemoAction games, available online and on CD-ROM. By encouraging players to embark on their very own “hemophilia adventure”, the games teach children how to prevent bleeds and manage hemophilia while learning about the clotting process, types of bleeds, factor infusions, and suitable physical activities. The focus, however, is on fun.

The HemoAction games are based on the tremendously popular HemoAction playing cards originally developed in 2003 by Frederica Cassis, a psychologist at the *Hospital das Clinicas* treatment centre in Brazil, and distributed by the WFH. The module features a classic memory game, a fill-in-the-blanks race to stop a bleed, a picture matching game where a factor-charged turtle saves the day, and a web-book that explains each card by telling a story about hemophilia. “The HemoAction cards are a great resource for me in my practice, for children and their families, and, I believe, for many of my colleagues around the world,” says Cassis. “It’s amazing to see them in motion in these new online games!”

These interactive games teach children and anyone who learns best through visual communication about hemophilia in a way that is fun and easy to understand. They can be used by parents, nurses, and other healthcare providers to reinforce key concepts about the disease and its management. “As they learn more, players can challenge themselves with higher levels of difficulty in each of the games,” says Elizabeth Myles, WFH director of communications and public policy. “Children learn not to be afraid of factor infusions and gain confidence and self-worth through educational play.” ■

The CD-ROM of the HemoAction games, and the HemoAction playing cards (available in English, Spanish, French, Portuguese, and Arabic), can be ordered through the WFH. To play online, visit www.hemoaction.org.

The HemoAction online games were developed with funding from Novo Nordisk and Pfizer.

NEWS FROM AROUND THE WORLD

WFH Regional Update



LEFT: Nurses training in Egypt. RIGHT: Home infusion demonstration in Belarus.

ASIA AND WESTERN PACIFIC

Bangladesh

A two-day physiotherapy workshop organized with the Hemophilia Society of Bangladesh led by Pamela Narayan (India) took place in December. In addition to training physiotherapists, the workshop educated more than 200 patients and families about regular exercise and physiotherapy, an important treatment option because factor concentrates are not available.

Cambodia

A national bleeding disorders workshop was organized by the National Pediatric Hospital and the Cambodia Hemophilia Association (CHA) in October, attended by over 120 doctors, laboratory technicians, and other healthcare professionals. Colleen McKay and Richard Scott from the Haemophilia Foundation of New Zealand met with CHA as part of a twinning assessment visit.

China

In October the 7th national hemophilia conference in Jinan had the highest registration ever (300+), and for the first time, 20 Hong Kong and Macau healthcare professionals attended. Hemophilia Home of China celebrated its 10th anniversary and held a national patient conference attended by 40 leaders from local hemophilia organizations. The World Federation of Hemophilia (WFH) had its first visit to central China at the Union Hospital in Wuhan City.

Thailand

In November, a national capacity building workshop for 80 patients, family members, and volunteer leaders in Bangkok was followed by a two-day leadership workshop in Sakon, Nakhon province, for groups in the northeast region. Jonathan Spencer and Peter Fogarty (Haemophilia Foundation Australia) attended. A Thai laboratory manual written by the Thai Global Alliance for Progress

(GAP) laboratory committee was completed and distributed nationwide.

EUROPE

European Haemophilia Consortium (EHC)

Medical and lay representatives from 33 countries attended the EHC annual conference in Lisbon, Portugal, in October 2010. Topics ranged from nursing to hepatitis C treatment.

Belarus

In December, the Belarusian Association of Haemophilia Patients organized a one-day educational workshop for children with hemophilia and their parents in Minsk. Topics included genetics, rehabilitation and orthopedic care, and coping with pain. The workshop concluded with a home infusion demonstration and a parent support session. Nadia Arkhipova, the vice-president of the Russian Hemophilia Society, and Dr. Mohamed Sampiev, an orthopedist from a Moscow-

based hemophilia treatment centre, were present.

Moldova

Approximately 40 patients and their families attended a patient workshop in Chisinau, facilitated by the Moldovan Public Society of Hemophilia president Ghenadie Ostrofet, as well as Radoslaw Kaczmarek and Michal Jamrozik, representatives from the Polish Hemophilia Society, the Moldovan Society's twinning partner. Read about Moldova's involvement in the Global Alliance for Progress (GAP) program on page 9.

Ukraine

Anna Griesheimer and Dr. Zimmermann from the German Hemophilia Society conducted a twinning assessment visit to Kiev in September. The WFH delegation met with the national member organization leaders and visited the adult and pediatric hemophilia treatment centres. There was also an advocacy meeting at the Ministry of Health.

AFRICA AND EASTERN MEDITERRANEAN

Algeria

The WFH organized a one-day meeting in Algiers in October that was attended by 12 hematologists representing 10 hemophilia treatment centres from around the country. The aim was to highlight some of the important aspects in establishing a national hemophilia program, including an updated registry and harmonized treatment guidelines.

Egypt

The WFH organized two workshops in Cairo on nursing and psychosocial aspects of hemophilia care in December. Frederica Cassis (Brazil), Elizabeth Paradis (Canada), and Mahmoud Aburiash (Saudi Arabia) delivered the training, which focused on introducing advanced methodology that could be used by participants in training other nurses or social workers.

Jordan

The WFH organized a dental training workshop in cooperation with the Jordan Hemophilia Society and Royal Medical Services in Amman in December. It was attended by 60 dentists from the Ministry of Health, Royal Medical Services, the University of Amman, and the private sector. Dr. Alison Dougall (Ireland) delivered the training, which focused on issues related to dental extraction for people with hemophilia in an environment with limited resources. She also attended the dental clinic at the Al-Bashir hemophilia treatment centre in Amman and assisted in examining and evaluating 10 patients.

Senegal

The WFH organized a regional physiotherapy workshop in Dakar for West African countries in October 2010, attended by physiotherapists from Mauritania, Cameroon, Ivory

Coast, Nigeria, Ghana, and Senegal. Led by WFH volunteers Christian Fondanesche (France) and Andrea Barlocher (Switzerland), it helped highlight physiotherapy as a major component of the multidisciplinary approach in hemophilia care and in strengthening the knowledge of participants.

South Africa

The WFH organized an orthopedic workshop in Johannesburg in November with the South African Hemophilia Foundation (SAHF) and the Medical and Scientific Advisory Council of the SAHF. Highlighting issues related to joint arthropathy among hemophilia patients, it attracted orthopedists and physiotherapists from all over the country, in addition to orthopedists from Lesotho and Botswana. WFH delegates met with the National Department of Health to discuss the importance of supporting the GAP program in South Africa, scheduled to begin in 2011. Read about South Africa's involvement in the Global Alliance for Progress (GAP) program on page 9.

AMERICAS

Cuba

The Cuban Society of Hemophilia (*Sociedad Cubana de Hemofilia*), in collaboration with the Instituto de Hematología e Inmunología, organized a workshop on hemophilia in December, attended by 40 members of the Cuban Society from various regions of the country. There was a lot of enthusiasm and exchange between medical professionals and patients and family members on how to improve quality of life.

Dominican Republic

In December the Foundation for the Support of People with Hemophilia (*Fundación Apoyo al Hemofílico*), along with two organizations that provide support



A case study at the physiotherapy workshop in Bangladesh.

for other diseases, organized "Help Us to Help", a Christmas breakfast inspired by the WFH Global Feast initiative. Instead of raising funds, they asked attendees to contribute by bringing gifts for children.

Panama

The Panamanian Foundation of Hemophilia (*Fundación Panameña de Hemofilia*), in conjunction with the Hospital del Niño, held a two-and-a-half-day training for parents, attended by five couples from different regions of Panama. The workshop was divided into two parts; the first discussed the psychosocial aspects of being a parent of a child with hemophilia. The second half of the workshop focused on understanding hemophilia, its management, and prevention of bleeds.

United States of America

The National Hemophilia Foundation's 62nd Annual Meeting was held in November in New Orleans, Louisiana.

Approximately 2,400 delegates attended sessions on topics ranging from ageing with hemophilia to research and technology updates to family planning. To read more about the meeting please see www.hemaware.org/story/nhf-annual-meeting-2010.

Uruguay

A three-day workshop organized by the Uruguayan Association of Hemophilia (*Asociación de Hemofílicos del Uruguay*) about rehabilitation for people with hemophilia and other bleeding disorders was held in November for physiotherapists and orthopedists. The main objectives were to encourage professionals in these areas to form part of a multidisciplinary team, train professionals, and conduct the first ever surgical procedure on a person with hemophilia in Uruguay. The surgery was a great success and the vice-minister of the Ministry of Health was present for the inauguration of the workshop. ■



Dental training in Jordan.

Empowering Others through Philanthropy

Eric Stolte

WFH FUND & RESOURCE DEVELOPMENT
COMMITTEE CHAIR

Empowerment, although very important, is one of those overused words whose meaning is becoming vague. I think of it as helping someone accomplish something for themselves. We empower when the other has the skill or capacity to move something forward. Philanthropy can be an engine for empowerment. Financial resources are often the key to increasing capacity or accessing needed development. Volunteering and philanthropic acts can also aid the empowerment of a vision or program. The World Federation of Hemophilia's (WFH) vision of Treatment for All is fuelled by the contributions of hundreds of people along with our corporate sponsors and donors. Working together, our mission to improve and sustain care will be fulfilled!

In 2005 we launched Global Feast, encouraging national member organizations (NMOs) to host events to raise awareness and funds to support local activities as well as the WFH's global mission, with revenues shared between the NMOs and the WFH. Recently the emphasis has shifted focus to raising awareness and educating people outside the bleeding disorders community. Many countries have participated in Global Feast in all WFH regions since 2005. The initiative continues to offer a way for individuals and NMOs to bring people together to learn, share, and support one another. Find out more at www.globalfeast.org.

A growing number of our NMOs are taking steps to help fulfill our mission through financial donations; empowering members of our global family for whom treatment is lacking. The Canadian Hemophilia Society (CHS) and more recently, the Haemophilia Foundation of New Zealand (HFNZ), have made support for our global mission a strategic priority. CHS pledged that two per cent of annual unrestricted revenues would be donated to the WFH each year. The HFNZ concluded that a specific amount, based upon revenues from HFNZ membership fees, would be donated annually to the WFH in support of the Global Alliance for Progress (GAP) program.

A loyal supporter of GAP since 2007, the Irish Haemophilia Society (IHS) remains deeply committed. They direct their annual donation to this core WFH program every year, and in 2010, their contribution was equal to 34 per cent of their annual fundraising revenues! The French Hemophilia Association (*l'Association française des hémophiles*), the Swiss Hemophilia Association, and the Egyptian Society of Hemophilia (ESH) have all made donations to the WFH, ranging up to US\$12,000 in a single year. The ESH has even made a three-year commitment!

A growing number of our NMOs are taking steps to help fulfill our mission through financial donations; empowering members of our global family for whom treatment is lacking.

One particularly inspiring contribution was sent from the Angamaly Chapter of the Hemophilia Federation India using the envelope insert from the April issue of *Hemophilia World*. The chapter is a relatively small treatment centre in Kerala, neither wealthy nor large. However, the impulse to participate—to reach out to help others and a larger cause—is what empowers the WFH mission.

All of these contributions help to train medical professionals, improve diagnosis, provide treatment to support WFH programs, and most importantly provide information, education, support, and hope to families whose loved ones struggle with the helplessness, pain, and stigma of bleeding disorders. This speaks to the growth of a philanthropic culture among the members of our global family. The compassionate donations from our NMOs empower all who have less but who believe in Treatment for All.

I urge all of our NMOs to consider what they can contribute through philanthropic efforts toward empowerment and Treatment



NMOs and chapters that empowered the WFH mission in 2010:

Canadian Hemophilia Society
Egyptian Society of Hemophilia
Haemophilia Foundation
of New Zealand
Irish Haemophilia Society
Swiss Hemophilia Association

CHAPTERS

India:

Hemophilia Society Angamaly Chapter

United States:

Delaware Valley Chapter
Hemophilia Center of Western
New York
Hemophilia of Iowa
Hemophilia of Georgia
Northern Ohio Hemophilia Foundation

for All those with inherited bleeding disorders, regardless of where they live.

To make a contribution, NMOs and chapters may:

- Go online at www.wfh.org
- Send a cheque to:
The World Federation of Hemophilia,
1425 René Lévesque West, Suite 1010,
Montréal, QC, Canada H3G 1T7
- Request information for a wire transfer by contacting Dolly Shinhat-Ross at dshinhat@wfh.org or by phone at +1-514-394-2821. ■

Calendar of Events 2011

World Hemophilia Day – 17 April

World Federation of Hemophilia
Tel.: +1-514-394-2822
Fax: +1-514-875-8916
Email: icerminara@wfh.org
Internet: www.wfh.org/whd

2011 HTRS Scientific Symposium

28–30 April – Chicago, U.S.A.

Hemostasis and Thrombosis
Research Society
Tel.: +1-312-503-8533
Fax: +1-312-503-4531
Email: nums-cme@northwestern.edu
Internet: www.htrs.org

IPFA/PEI 18th Workshop on “Surveillance and Screening of Blood Borne Pathogens”

24–25 May – Dublin, Ireland

International Plasma Fractionation
Association/Paul-Ehrlich-Institut
Tel.: +31-20-512-3561
E-mail: ipfa@sanquin.nl
Internet: www.ipfa.nl/ipfa/ipfa.nsf

World Blood Donor Day – 14 June

World Health Organization

Internet:
www.who.int/worldblooddonorday

PPTA Plasma Forum

14–15 June – Washington, D.C., U.S.A.

Plasma Protein Therapeutics Association
Tel.: +1-410-263-2298
Email: ccash@pptaglobal.org
Internet: www.pptaglobal.org

21st Regional Congress of the ISBT

18–22 June – Lisbon, Portugal

International Society of Blood Transfusion
Tel.: +31-20-679-3411
Fax: +31-20-673-7306
Email: lisbon@isbtweb.org
Internet: www.isbtweb.org/lisbon

XXIII ISTH Congress

23–28 July – Kyoto, Japan

International Society on Thrombosis and
Haemostasis

Tel.: +81-3-3508-1202
Fax: +81-3-3508-0820
Email: isth2011@convention.jp
Internet: www.isth2011.com

World Hepatitis Day – 28 July

World Hepatitis Alliance
Internet: www.worldhepatitisalliance.org

XXII Congreso Internacional del Grupo CLAHT

1–3 September – Montevideo, Uruguay

Cooperativo Latinoamericano de
Hemostasis y Trombosis
Tel.: +598-2-900-58-28
Fax: +598-2-902-42-64
Email: claht2011@personas.com.uy
Internet: www.congresoclaht2011.com/

Seventh WFH Global Forum on the Safety and Supply of Treatment Products for Bleeding Disorders

22–23 September – Montreal, Canada

World Federation of Hemophilia
Tel.: +1-514-394-2820
Fax: +1-514-875-8916
Email: dandre@wfh.org
Internet: www.wfh.org

EHC Conference 2011

7–9 October – Budapest, Hungary

European Haemophilia Consortium
Internet: www.ehc.eu

NHF 63rd Annual Meeting

10–12 November – Chicago, U.S.A.

National Hemophilia Foundation
Internet: www.hemophilia.org

World AIDS Day – 1 December

National AIDS Trust
Internet: www.worldaidsday.org

ASH Annual Meeting

10–13 December –
San Diego, U.S.A.

American Society of Hematology
Tel.: +1-202-776-0544
Fax: +1-202-776-0545
Internet: www.hematology.org

Demystifying Clotting Factor Concentrates for Regulators



WFH Senior Public Policy Officer Mark Brooker (right) with Dr. Hannelore Willkommen, a speaker at the workshop.

Mark Brooker
WFH SENIOR PUBLIC POLICY OFFICER

The World Federation of Hemophilia (WFH) Workshop on the Regulation of Treatment Products for Bleeding Disorders took place in Rio de Janeiro, Brazil, in November. Among the 73 participants were 30 government officials from 18 countries in Latin America and leaders in the hemophilia community in the region. International experts explained factors affecting the quality and safety of hemophilia treatment products, industry quality programs, and licensing, regulation and control of plasma by major regulatory agencies. Two of the most popular sessions included contract fractionation and biosimilars respectively.

This was the fifth such workshop for the WFH. The workshops, based on the WFH *Guide for the Assessment of Clotting Factor Concentrates*, are designed to educate the people who license and purchase treatment products for bleeding disorders. Because of the small patient community, high cost, complicated manufacturing process, and the transmission of infectious diseases, clotting factor concentrates can be intimidating for regulators. The workshops aim to increase access to products by showing regulators how to evaluate these rare biological products. ■

The WFH thanks Baxter, Biogen Idec Hemophilia, CSL Behring, Green Cross, Grifols, LFB, and Talecris for supporting the workshop.



WFH Congress 2012 8–12 July 2012 – Paris, France

World Federation of Hemophilia

Tel.: +1-514-875-7944 Email: info2012@wfh.org
Fax: +1-514-874-8916 Internet: www.wfhcongress2012.org

Thank You

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

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Jan Willem André de la Porte

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Pfizer
Talecris

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Bayer

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Nordisk

Laboratory web section:

Talecris

VWD web section: CSL

Behring, Grifols, LFB

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TOH Monograph: CSL

Behring

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Pfizer

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Hemophilia

Susan Skinner Memorial Fund: The
Hemophilia Alliance

VWD Outreach Project: LFB

World Hemophilia Day

Baxter, Bayer, Biogen Idec

Hemophilia, Inspiration

Biopharmaceuticals, Novo Nordisk

Global Research Forum

Baxter

Bayer

Biogen Idec Hemophilia

CSL Behring

Grifols

Novo Nordisk

Octapharma

Pfizer

ORGANIZATIONS

Canadian Hemophilia Society*

Egyptian Society of
Hemophilia*

Haemophilia Foundation of
New Zealand*

* WFH is proud to acknowledge the support of our National Member Organizations.

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HEMOPHILIA WORLD WOULD LIKE TO HEAR FROM YOU!

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

The Editor, Hemophilia World

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