The World Federation of Hemophilia (WFH) is pleased to announce that Alain Weill was elected president at its General Assembly on July 13, 2012. Weill lives in France and has extensive professional experience in management and business in an international environment. Now retired, he worked for over 30 years with Air France where he was chief of staff to the chief executive. He has experienced many different cultures, and has lived in India, the United Kingdom, Belgium, and the Netherlands.

Weill first encountered hemophilia when his son was diagnosed with severe hemophilia A. He has been involved with the Association française des hémophiles (AFH) and was elected as an AFH board member in 2006. He served as an elected member of the Steering Committee of the European Haemophilia Consortium, and was selected by the European Commission to represent patients at EUCERD (European Committee of Experts in Rare Diseases). He was also a member of the Organizing Committee for the WFH 2012 World Congress in Paris.

“Despite 50 years of efforts, we still face an unsatisfactory situation in many countries in terms of diagnosis, care, and product availability,” Weill said. “The work is not yet complete. My objective is that every year brings us closer to our vision of Treatment for All.”
The WFH 2012 World Congress brought together the global bleeding disorders community, in record numbers, in Paris, France. This year’s Congress also took on a special meaning with the launch of the 50th anniversary of the World Federation of Hemophilia (WFH) and the start of its Close the Gap campaign. With over 5,400 delegates, from over 130 countries, the session rooms, poster area, and exhibition hall were filled to capacity.

The robust medical program was presented by leading experts in hemophilia research and it included plenary lectures on new approaches to the management of hepatitis C, personalized prophylaxis, WFH research initiatives, developing models of hemophilia care, and the use of long-acting products versus gene transfer. The multidisciplinary program covered topics on family perspectives and support, psychosocial models in hemophilia, ageing with hemophilia, and women with inherited bleeding disorders.

This Congress was organized by the WFH and was hosted by the Association française des hémophiles (AFH). The AFH was honoured to announce that Monsieur François Hollande, president of the French Republic, bestowed his high patronage on the XXX International Congress of the World Federation of Hemophilia. Congress president Norbert Ferré, honorary Congress president Edmond-Luc Henry, WFH president (2004-2012) Mark W. Skinner, medical program co-chair Prof. Claude Négrier, and Dominique Bertinotti, a representative of the French government and junior minister for families, welcomed the global bleeding disorders community during the Opening Ceremony.

"Holding a World Congress is truly a great honour for the host country," said Mr. Henry. "The WFH 2012 World Congress also celebrated the jubilee of the World Federation of Hemophilia, adding to the symbolic force of this Congress for the French Hemophilia Society."

In honour of the WFH’s 50th anniversary, a number of special guests attended the Congress including Jan Willem André de la Porte, WFH patron; Gina Schnabel, daughter of WFH founding president Frank Schnabel; Patsy Carman, wife of Charles Carman, WFH president from 1988-1993; and Brian O’Mahony, WFH president from 1994-2004.

There were many opportunities for Congress delegates to socialize, with an engaging cultural event that was put together by the AFH. In addition, the farewell dinner was a sold-out affair at the Pavillon Dauphine.

The WFH and our local hosts, the AFH, thank the Congress participants for their support—because of it, the WFH 2012 World Congress was a great success. It was a perfect way to mark the beginning of this anniversary celebration and reflect upon the achievements of the global bleeding disorders community. We look forward to the next Congress in Melbourne, Australia, in 2014.

Craig T. McEwen
WFH CONGRESS AND MEETINGS DIRECTOR

WEBCASTS OF CONGRESS SESSIONS
Registered Congress participants can now view webcasts of selected sessions from the WFH 2012 World Congress program. In October, national member organizations, hemophilia treatment centre staff, and WFH members will also have access to this webcasting service, which includes full media presentations with animated slides, reproduction of the speaker’s laser pointer movements, and embedded videos. For selected talks, PowerPoint slides are also available for download.

Go to www.wfh.org/congress to access the webcasts of the WFH 2012 World Congress.

Presentations are also available on Apple and Android mobile devices via the TALKS on the GO™ webcast application. Please visit www.talksontheego.com or download the application through the Apple App store or Google Play store.

If you have any difficulties accessing the webcasts, please contact the MULTIWEBCAST support team by email: support@multiwebcast.com.
MARK W. SKINNER CHALLENGES CURRENT MODELS OF CARE TO MEET GLOBAL NEEDS

Elizabeth Myles  
WFH COMMUNICATIONS AND PUBLIC POLICY DIRECTOR

Speaking at the opening session of the WFH 2012 World Congress, World Federation of Hemophilia (WFH) president (2004-2012) Mark W. Skinner evaluated current practices and models for treating hemophilia and related bleeding disorders, which affect one in 1,000 people worldwide.

“Treatment has come a long way since 1963, when the WFH was founded,” he said. “We are on the cusp of a new revolution in treatment,” with breakthroughs on all fronts over the next few years, ranging from viral-inactivated cryoprecipitate, biosimilars, longer lasting products, and the real prospect of a cure through gene therapy.

Skinner said that now is the time to rethink current definitions of optimal care and he challenged current thinking on minimum desirable clotting factor levels, which is currently 1 per cent, suggesting that we should incrementally increase levels to 3, 5, and perhaps ultimately 15 times higher to fully prevent bleeding and joint damage from occurring.

“This standard is based on what was achievable given product supply constraints, economics, and product half-life limitations. “Improving patient quality of life should drive treatment decisions, not economics or supply constraints,” he concluded.

Making optimal treatment affordable was the next hurdle Skinner addressed. He encouraged manufacturers to adopt a new 21st century business model based on high volume and lower margins. He also challenged government, payers, and manufacturers to “rise to the challenge by improving market accessibility and adopting market-based business solutions to achieve it.”

Skinner noted that challenges in economically less-developed countries are even greater, due to the high cost of products. Using data collected by the WFH over the last 10 years, he showed that patients in poorer countries are far less likely to be diagnosed, treated, or survive into adulthood.

To mark the WFH’s 50th anniversary in 2013, Skinner announced that the WFH will launch a new decade of the Global Alliance for Program (GAP) Program, to identify 50,000 new patients with bleeding disorders by 2022, with 50 per cent of those in impoverished or underserved countries.

The WFH will also launch a new program, the Cornerstone Initiative, to work in the poorest countries to improve basic aspects of care and lay the cornerstone for the development of care. This 10-year plan specifically targets those countries and regions of the world that have previously been underserved and where the gap in care is greatest. It will target countries at the lower end of the economic spectrum, laying the basic foundation upon which future development can occur. The program will focus on improving diagnostic capacity, providing basic training in the management of bleeding disorders, and strengthening patient organizations.

This plenary took on a special significance for Skinner, as he completed his last term as WFH president during this Congress.

To view this plenary as a webcast, please visit www.wfh.org/congress.

The smaller the gap between the patient's expectations and their achievements, the higher the quality of life.”

— Sylvia von Mackensen, MD
Treatment of bleeding in patients with inhibitors
Many variables enter into the treatment of acute bleeding in patients with inhibitors. Cost, site, and severity of hemorrhage; inhibitor level; product efficacy and safety; and patient age all must be considered, said Alessandro Gringeri, MD (Italy).

The crucial component in bleeding management is timeliness. Where we do not achieve an appropriate clinical response, we can continue the same treatment. However, if we do not get a response, we need to increase the dose or consider a different product, reported Gringeri.

Roseline d’Orion, MD (France), said achieving surgical hemostasis in patients with inhibitors is a challenge. Successful hemostasis is achievable with both rFVIIa and FEIBA, in elective and emergency surgeries. Cost of products to cover surgery, which is higher in inhibitor than non-inhibitor patients, and inter-individual variability of efficacy of the different products should be considered. Prolonged treatment to minimize the risk of post-operative bleeding is often required, which can be difficult to achieve in countries with significant resource constraints.

OUTCOME ASSESSMENT
Brian Feldman, MD (Canada), discussed how applying standardized outcome measurement tools as part of routine clinical practice allows clinicians to be more objective when evaluating how certain therapies work in people with hemophilia. In turn, this can improve quality of care. Feldman gave examples of specific hemophilia outcome measurement tools that have practical uses in clinical settings.

Musculoskeletal assessment tools
Pradeep M. Poonoose, MD (India), and Shyamkumar N. Keshava, MD (India), addressed limitations of some “legacy” outcome assessment tools. Poonoose said one must first decide what needs to be measured—structure or function. “Radiological scores without functional status information may cause the researcher to make erroneous assumptions.” Keshava added, “Radiography provides a baseline assessment and can reveal osteochondral changes, but not soft tissue changes. MRI is more complex and best for detail of soft tissue and osteo-cartilage changes, and ultrasonography can be used for assessing soft tissue changes and is relatively inexpensive.”

Health-related QoL
“The smaller the gap between the patient’s expectations and their achievements, the higher the quality of life,” said Sylvia von Mackensen, MD (Germany). “Assessment of these gaps can help identify specific healthcare needs,” she said.

Kathelijn Fischer, MD (the Netherlands), told the audience that treatment should be individualized to achieve the best outcomes for the patient. “Look at the bleeding pattern of the patient, step up aggressively, and engage in dialogue with the patient and the team,” she said.

Bleeding scores
Alberto Tosetto, MD (Italy), presented an analysis of quantitative bleeding assessment tools (BAT), including the Vicenza BAT, which grades epistaxis, cutaneous symptoms, minor wounds, oral cavity bleeding, and hemorrhage on a scale of one to three in terms of severity. Data shows BATs can be used for descriptions of bleeding phenotypes, for research purposes, and in diagnosis of von Willebrand disease, Tosetto said. Their use in other bleeding disorders needs to be validated.

HEPATITIS C VIRUS (HCV)
Fabien Zoulim, MD (France), a recognized expert in the field of antiviral therapy and drug resistance, discussed the development of non-invasive tools to assess the stage of liver fibrosis stages, as well as a new triple therapy regimen that has been shown to yield significant improvements in treating naïve patients with HCV genotype 1 infection, compared with the existing gold standard of interferon and ribavirin based protocols. Updates on ongoing clinical trials, including one in HIV and HCV co-infected patients, were also presented.

“The WFH has a unique opportunity to develop an internationally reputable bleeding disease research program … in collaboration with other international groups that are more experienced in the research arena.”

— David Lillicrap, MD

“Look at the bleeding pattern of the patient, step up aggressively, and engage in dialogue with the patient and the team.”

— Kathelijn Fischer, MD
COMPREHENSIVE CARE
The hemophilia community was a pioneer in developing a comprehensive approach to patient care, and that model is the foundation for the chronic disease management strategy that is widely used in health care today. During the session on developing models of hemophilia care, the human and financial resources necessary to deliver comprehensive care were described and its central role in the WFH 2012-2014 strategic plan and research program was discussed.

WFH RESEARCH PROGRAM
In his plenary, David Lillicrap, MD (Canada), outlined the WFH’s new research program, which aims to provide infrastructural support for clinical observational and other investigative studies relating to inherited bleeding disorders around the world.

“The WFH has a unique opportunity to develop an internationally reputable bleeding disease research program,” said Lillicrap. “In collaboration with other international groups that are more experienced in the research arena, for example the International Society on Thrombosis and Haemostasis, the WFH provides the complementary global intelligence to successfully promote knowledge discovery in the field of inherited bleeding disorders.”
Women With Bleeding Disorders

“Women’s bleeding disorders are debilitating, bear high-economic burden, and carry the risk of mortality if untreated,” said Rochelle Winikoff, MD (Canada). She added that developing a multidisciplinary care team ensures the patient of quality care.

In setting up a multidisciplinary team, Winikoff outlined five “bullet” points: Identify the patients’ and clinicians’ needs, consider the setting and resources, lay the groundwork by knowing the players and their roles, establish operational procedures, and secure financing.

Ann-Marie Nazzaro (U.S.A.) said women have unique bleeding issues at every stage of life. The Centers for Disease Control and Prevention data shows consistent growth in women registered at hemophilia treatment centres. A recent study shows that 52 per cent of women with a bleeding disorder are now diagnosed by the time they are 12 years old.

Rare Bleeding Disorders (RBD)

Although there has been progress in the diagnosis and treatment of RBD, much remains to be done.

“It is very important to provide information and education for patients and for doctors so that these disorders can be properly diagnosed and managed … Laboratory diagnosis remains a considerable challenge in many areas of the world, even for von Willebrand disease.”

— Paula Bolton-Maggs, MD

There are many webcasts and other educational materials, such as the State of the Art publication and abstracts, available from this Congress on www.wfh.org. We would appreciate any feedback and suggestions for the program content for the WFH 2014 World Congress. For more information on how to access the WFH 2012 World Congress webcasts, read more on page two of this issue.

Economics of Hemophilia Care

National hemophilia registries do more than aid in diagnosis and treatment. They can also be powerful economic tools in an increasingly cost-conscious, cost-contained healthcare environment. Angelika Batorova, MD (Slovakia), said data show that low-income countries like Slovakia, Croatia, and Iran that have well-organized national registries also have rates of hemophilia diagnoses and factor VIII use comparable with high-income countries.

Keith Tolley (U.K.) said national registries can collect information on patients’ quality of life, which is a key component of health technology assessments (HTAs). These assessments help governments and other payers determine the value of treatment and drug therapies by examining their short- and long-term consequences in terms of health and resource use. At this point, cost-effectiveness evidence is limited and inconclusive and national registries should be supported to provide data appropriate for such analysis.

Daniel Arnberg (Sweden) described the first national HTA of hemophilia A care which was conducted in Sweden. This included a study of the use and clinical effectiveness of factor VIII products. Amongst the findings were that prophylaxis is effective but that there is insufficient evidence as to the optimal cost and clinically effective dosage regimen. Interestingly, there is no national hemophilia registry in Sweden and the HTA report recommended one be set up to support further analysis.
Nearly 50 years ago, the World Federation of Hemophilia (WFH) was founded by Frank Schnabel, a Montreal-based businessman born with severe hemophilia A. His vision was to improve treatment and care for “the hundreds of thousands of hemophiliacs” worldwide through a new international organization.

On June 25, 1963, Frank Schnabel convened a global meeting in Copenhagen, Denmark, with representatives from 12 countries, and the rest is history. Today, the WFH represents national patient organizations in 122 countries.

At the WFH 2012 World Congress, we kicked off our anniversary celebrations with the launch of the first in a series of 12 video podcasts. “The Winning Coalition,” produced and directed by Marilyn Ness, tells the story of building sustainable care in Senegal, and how doctors, patient leaders, governments, volunteers, and the WFH work together to improve care. This video is available on YouTube and the WFH website, and others will be released throughout 2012 and 2013.

Haemophilia, the official journal of the WFH, is publishing a series of commemorative articles to mark the WFH’s 50th anniversary, one per issue, throughout 2012 and 2013. These articles capture key moments in hemophilia care, such as Margareta Blomback’s recollections on her research into von Willebrand disease, Ulla Hedner’s story on the development of activated factor VII, and others.

50th anniversary materials are available at www.wfh.org/50.

HOW YOU CAN GET INVOLVED WITH OUR 50th ANNIVERSARY:

- Share your stories, photographs, and memorabilia with the WFH
- Show podcast videos to your members or share links on your website
- Celebrate your organization’s history and its history with the WFH
- Participate in World Hemophilia Day 2013, dedicated to the WFH 50th anniversary
- Sign up at www.wfh.org to receive the latest updates on the 50th anniversary activities

The WFH is grateful to our corporate partners for their support of the WFH 50th anniversary.
The Patron’s Challenge: All Donations Will Be Tripled

Jan Willem André de la Porte announced a remarkable challenge to the entire bleeding disorders community—that every dollar donated to the campaign, beginning at Congress, will be matched 2:1. "I am pledging half a million dollars—but alone it is not enough. We must all help. I hope that my personal pledge will inspire our community to give generously so that together we can close the gap in care and achieve our vision of Treatment for All.”

Contributions to the WFH Close the Gap campaign can be made online at www.wfh.org/closethegap.
EXCEPTIONAL VOLUNTEERS RECOGNIZED DURING WFH AWARDS CEREMONY

Sarah Ford
WFH COMMUNICATIONS MANAGER

The World Federation of Hemophilia (WFH) recognized outstanding volunteers from around the world in the WFH Awards Ceremony held during the WFH 2012 World Congress.

The Inga Marie Nilsson Award, sponsored by Octapharma, is given to an individual who has contributed substantially with leadership and initiative through a project which advances the WFH mission. Alok Srivastava, MD (India), was given this award based on his many contributions to the bleeding disorders community and the WFH, including the revision of the WFH’s Guidelines for the Management of Hemophilia. This is the second time that he has received this award.

Piet de Kleijn (the Netherlands) was the winner of the Pietrogrande Prize. This prize recognizes a healthcare professional who has notably contributed to furthering the mission and goals of the WFH Musculoskeletal Committee.

Horacio Caviglia, MD (Argentina), was awarded the Henri Horoszowski Award, selected by the Musculoskeletal Committee, for his paper entitled “Pseudotumor surgery in haemophilia A patients: Comparative results between inhibitor and non-inhibitor patients.”

The Henri Chaingneau Prize of the Association française de hémophiles was awarded to Edward G. Tuddenham, MD (U.K.), for his clinical research in the fields of factor VIII gene cloning, factor VIII gene mutations, factor IX gene therapy, and multiple other aspects of hemostasis and their pathologies.

The Twins of the Year Awards are given annually, by the WFH, to recognize the most exceptional organization and treatment centre twinning partnerships. This program, sponsored by Pfizer, pairs hemophilia organizations or medical centres, in developing and developed countries, to encourage the transfer of skills, resources, and information.

There were two sets of Treatment Centre Twins of the Year for 2010: The Hemophilia Society Delhi Chapter (India) and The Manitoba Pediatric Bleeding Disorders Program (Canada); and The University of Yaoundé (Cameroon) and the University of Geneva (Switzerland). The 2010 Organization Twins of the Year Award went to the Tunisian Hemophilia Association and the Quebec Chapter of the Canadian Hemophilia Society.

The Treatment Centre Twins for 2011 award recipients were the Estella Pediatric Hematooncology Center Manado (Indonesia) and the Van Creveldkliniek, University Medical Center Utrecht (the Netherlands). The 2011 Organization Twins Award went to the Cambodia Haemophilia Association and the Haemophilia Foundation of New Zealand.

The Susan Skinner Memorial Fund Scholarship for 2011 was awarded to Alexandra Johnson (U.S.A.) and Aleksandra Ilijin (Serbia) for 2012. The scholarship was established as an endowment to support the training and education of young women with bleeding disorders or who are carriers, who demonstrate outstanding leadership potential to become leaders in their country and future leaders in the bleeding disorders community.

Several new awards were inaugurated at this Congress Awards Ceremony. The Advocacy Recognition Award, launched in 2010 as part of the Advocacy in Action program, which is funded by Baxter, aims to highlight a successful advocacy campaign by one WFH national member organization. This year’s recipient was the Federación de Hemofilia de la República Mexicana for their advocacy campaign to secure free treatment and care for uninsured children, under the age of 10, who have hemophilia and VWD.

The Young Researchers Award, given to researchers under 35 who have submitted highly rated abstracts to Congress, was awarded to Benjamin Bluth (U.S.A); Corien Eckhardt, Samantha Gouw, and Perrine Limerg (the Netherlands); and James Porter (U.K.).

The Christine Lee Haemophilia Journal Award was also inducted this year. This award will be given out annually, starting in 2013, and will be presented to a young researcher in recognition of the best article published in the official journal of the WFH in a calendar year. It is sponsored by Wiley-Blackwell and will include a prize of US$3,000.

Christine Lee, MD (U.K.), founder of the Haemophilia Journal, was awarded the WFH’s Lifetime Achievement Award, only the second recipient of this award since it was created in 2006. Lee was consultant and director of the Royal Free Haemophilia Centre and Haemostasis Unit from 1987 until her retirement in 2005. Lee is also the founding editor of the journal Haemophilia, which was launched in 1995. She is emeritus professor of haemophilia, University of London, and has published more than 300 peer-reviewed scientific papers about hemophilia and edited eight books including the Textbook of Hemophilia.
The International Healthcare Volunteer Award was given to Piet de Kleijn (the Netherlands). de Kleijn has been a dedicated member of the hemophilia family for many years. Since 1979, he has practiced and researched physical therapy in hospitals in the Netherlands and has been a committed WFH volunteer, a member of the Musculoskeletal Committee, and conducted WFH workshops in many countries.

Martha Patricia Monteros Rincón (Mexico) won the International Frank Schnabel Volunteer Award. Over the last two decades, Monteros has helped improve access to care and treatment for the bleeding disorders community in Mexico. She has advocated for insured care for children with bleeding disorders in her country, and has promoted care and treatment for all patients in the country. It was especially meaningful that Gina Schnabel, Frank Schnabel’s daughter, was one of the presenters of this award.

The WFH Awards Ceremony closed with a touching tribute to WFH president (2004-2012) Mark W. Skinner, given by Bruce Evatt, MD, WFH Lifetime Achievement Award recipient in 2006. Evatt thanked Skinner, on behalf of the global bleeding disorders community, for his dedication and commitment to the WFH and spoke memorably of Skinner’s concern for patients in developing countries and the passionate response that has driven his tenure over the last eight years. A special book was presented to Skinner which included photos and messages from the individuals that he has met and worked with during his time with the WFH. Skinner received a standing ovation from the audience.

The WFH wishes to congratulate all the 2012 award recipients. A special thanks goes to Aris Hashim, chair of the WFH Awards Committee, for hosting this ceremony. For photographs and more information, please visit www.wfh.org.

Antonietta Colavita
WFH ANNUAL CAMPAIGN MANAGER

The World Federation of Hemophilia (WFH) would like to extend a tremendous thank you to the more than 200 delegates who helped launch our Close the Gap campaign at the WFH 2012 World Congress in Paris.

During Congress, close to US$40,000 was raised to help close the gap in care worldwide, with gifts ranging from 20 centimes to US$5,000.

We would like to extend a special thank you to WFH patron Jan Willem André de la Porte for his remarkable generosity and inspiring challenge. André de la Porte has matched 2:1 every dollar donated at Congress. Every contribution has been tripled and the total raised at the WFH 2012 World Congress is an outstanding US$120,000!

Join us on Facebook to see photos of Congress delegates making their mark on the WFH World map.

Donations can continue to be made at any time online at www.wfh.org and will still be eligible to be matched by our patron. Your gift will be tripled.

Congratulations to campaign winners at Congress:

- Daily draw prizes were won by Julie Heinrich (U.S.A.), Debbi Adamkin (U.S.A.) and Woet L. Gianotten (the Netherlands).
- Uroš Brezavšček (Slovenia) won the grand prize of return travel, accommodation, and registration for the WFH 2014 World Congress in Melbourne, Australia.
- The WFH World Cup was awarded to Panama as the country with the biggest heart (the most donors at Congress, relative to population size). Second place was Canada (which won in 2010), and third was Bahrain.

Thank you to the Association francaise des hémophiles and the Haemophilia Foundation Australia who donated the draw prizes.

Over 60 delegates joined up or renewed their membership at Congress. To mark the 50th anniversary of the WFH, these members will receive 50 per cent more on their membership cycle—18 months of membership for the price of 12. In addition, five names were drawn from among these to receive a complimentary subscription to Haemophilia, the official journal of the WFH. Congratulations to Claudia S. Lorenzato (Brazil); Shubhranshu S. Mohanty (India); Esther Muntu (Indonesia); Pamela Narayan (India); and David Stephensen (U.K.). The WFH would like to thank Wiley-Blackwell for providing these five complimentary subscriptions.

Sign up for WFH membership and find out more about benefits at www.wfh.org.

We are deeply grateful to everyone who helped make the WFH 2012 World Congress the most successful to date. Together we will close the gap.
WFH YOUTH DELEGATES HAVE A STRONG VOICE AT GLOBAL NMO TRAINING

Anabella Zavagno
WFH PROGRAM COORDINATOR, TWINNING & GLOBAL NMO TRAINING

Over 100 participants from 85 countries attended the WFH Global Training for National Member Organizations, held in Marne-la-Vallée, France, from July 5-7. There were many new faces at the training, including 15 youth delegates funded by WFH fellowships and 2 recipients of the Susan Skinner Memorial Fund scholarships.

At a time when many associations are having difficulty engaging youth, it was inspiring to see the enthusiasm and involvement of these young leaders. “These young people are ready to take on a greater role in their own societies,” said facilitator and WFH Executive Committee member Deon York (New Zealand).

The training sessions aimed to help patient leaders expand their skills and knowledge through a mix of workshops and presentations on such topics as clinical research, fundraising, youth involvement, organizational assessment, conflict management, and advocacy skills.

A screening was held of the film Bad Blood: A Cautionary Tale, which chronicles the HIV pandemic in the US hemophilia community. Following the film, director and producer Marilyn Ness, WFH president (2004-2012) Mark W. Skinner, National Hemophilia Foundation CEO Val Bias, and Polish Hemophilia Society board member Radoslaw Kaczmarek led a discussion on the value of the film as a tool to raise awareness and advocate for patient involvement when decisions are being made about their treatment and care.

REVISED WFH GUIDELINES FOR THE MANAGEMENT OF HEMOPHILIA PUBLISHED IN HAEMOPHILIA

Jennifer Laliberté
WFH EDUCATIONAL MATERIALS MANAGER

Hemophilia is a rare disorder that is complex to diagnose and manage. By compiling the second edition of its Guidelines for the Management of Hemophilia, the World Federation of Hemophilia (WFH) aims to provide practical, evidence-based guidance to healthcare providers, government authorities, and patient organizations seeking to initiate and/or maintain hemophilia care programs.

We also hope they will encourage practice harmonization around the world and, where recommendations lack adequate evidence, stimulate appropriate studies.

The first edition of Guidelines for the Management of Hemophilia, published in 2005 by the WFH, proved useful for those looking for basic information on the comprehensive management of hemophilia. The need for revision arose for several reasons, the most significant of which was the need to support practice recommendations with the best existing evidence. There are recent high-quality data from randomized controlled trials establishing the efficacy and superiority of prophylactic factor replacement over episodic treatment, for example. There is also greater recognition of the need for better assessment of outcomes of hemophilia care using newly developed, validated, and disease-specific clinimetric instruments. This revised version addresses these issues and includes necessary updates to all other sections.

The issue of universal applicability, given the diversity of health services and economic systems around the world, deserved careful consideration. Our strongly held view is that the principles of management of hemophilia are the same all over the world. The differences are mainly in the doses of clotting factor concentrates (CFC) used to treat or prevent bleeding, given that the costs of replacement products comprise the major expense of hemophilia care programs. Recognizing this reality, these guidelines continue to include a dual set of dose recommendations for CFC replacement therapy, which are based on published literature and practices in major centres around the world. However, the lower doses recommended may not achieve the best results possible and should serve as the starting point for care to be initiated in resource-limited situations, with the aim of gradually moving toward more optimal doses, based on data and greater availability.

The WFH would like to thank Alok Srivastava, MD, and the expert working group for their hard work and dedication to this project. The revised guidelines are now available in the journal Haemophilia and at www.wfh.org.
At the 31st General Assembly, held on July 13, the World Federation of Hemophilia (WFH) welcomed five new member organizations, bringing the total number of countries represented to 122. National patient organizations from Afghanistan, Mauritius, Montenegro, Uganda, and the United Arab Emirates were voted in as associate national member organizations. In addition, associate member organizations from Cameroon, Kyrgystan, Oman, and Qatar became full national member organizations (NMOs).

Alain Weill (France) was elected WFH president during the General Assembly. Read more about Weill on page one of this issue. Other Executive Committee members that were elected include Alok Srivastava, MD (India), as vice-president medical; Eric Stolte (Canada), vice-president finance; Magdy El Ekiaby, MD (Egypt), and Alessandro Gringeri, MD (Italy), as medical members; and David Silva (Spain) and Pam Wilton (Canada) as lay members.

Following the General Assembly, Margareth Castro Ozelo, MD (Brazil), was appointed by the Executive Committee to complete a two-year medical term left vacant by Srivastava’s election as vice-president medical. In addition, Carlos Safadi Márquez (Argentina) was co-opted onto the WFH Executive Committee.

Congress sites for both 2016 and 2018 were also voted on by WFH NMOs. The National Hemophilia Foundation (NHF) successfully bid to host the WFH 2016 World Congress in Miami, Florida. The UK Haemophilia Society won the bid to hold the WFH 2018 World Congress in Glasgow, Scotland. By selecting the WFH 2018 World Congress site this year, the WFH will be able to announce dates sooner and avoid potential conflicts with other meetings.

Thank you to outgoing executive members
At this General Assembly, a number of Executive Committee members completed their terms. On behalf of the global bleeding disorders community, we would like to thank them for their service to the WFH.

Mark W. Skinner, WFH president
Alison Street, MD, WFH vice-president medical
Rob Christie, WFH vice-president finance
Paula Bolton Maggs, MD, medical member
Johnny Mahlangu, MD, medical member

Thank you for your commitment, leadership, and inspiration.
DEDICATED VOLUNTEERS AND DONATED CLOTTING FACTOR CONCENTRATES PROVED ESSENTIAL TO CONGRESS PARTICIPANTS IN NEED

Maria Carolina Arango  
PROGRAM OFFICER—HUMANITARIAN AID & ACCREDITATION

The World Federation of Hemophilia (WFH) partnered with the Association française des hémophiles (AFH) to ensure all people with bleeding disorders had treatment readily available throughout the Global NMO Training, the WFH 2012 World Congress, and the WFH General Assembly.

A total of 681,000 international units (IU) of clotting factor concentrates were kindly donated by Baxter, Bayer Healthcare, CSL Behring, LFB, Novo Nordisk, Octapharma, and Pfizer for use in the treatment rooms during these events.

A team of dedicated volunteer doctors, nurses, and physiotherapists played a vital role in ensuring that the planning and operation of the treatment room was successful. Patients who visited the treatment room were first greeted and examined by a doctor who would prescribe treatment and refer them to the integrated physiotherapy room on an as-needed basis. Wheelchairs were also made available to patients to ensure a more accessible Congress experience.

The WFH would like to thank our donors for their continued commitment to making the treatment room possible and express our profound appreciation to the AFH and the exceptional team of medical professionals for the remarkable service they provided.

Michelle Grady  
WFH COMMUNICATIONS OFFICER

The WFH 2012 World Congress would not have been possible without the hard work and determination of the Congress host, the Association française des hémophiles (AFH) and a dedicated group of local volunteers.

Special recognition needs to be given to the Congress host, the AFH, for their time, effort, and devotion in helping to ensure the undeniable success of the Congress. Made up almost entirely of volunteers, the AFH is one of the original founding members of the World Federation of Hemophilia (WFH) and a member of the European Haemophilia Consortium.

“It has been a great honour for the AFH to host such an important scientific meeting,” said Norbert Ferré, Congress president and president of the AFH. “Not only does it testify to the commitment of all the volunteers within the organization, it also recognizes the expertise of the AFH as well as the French scientific community and health authorities who support us.”

Nearly 70 volunteers were recruited and trained by the AFH, under the direction and management of Michel Du Laurent de la Barre. Volunteers prepared delegate bags, helped answer delegates’ questions regarding WFH events at Congress, distributed the newspaper Hemophilia Daily, and greeted Congress delegates each day with both enthusiasm and kindness.

The WFH is also grateful to Congress sponsors. For a full list of these sponsors, go to page 16. As we close the books on our most successful Congress to date, the WFH would like to extend a heartfelt thank you to all who gave their time and dedication—it would have been impossible without them.

The AFH at their booth in the exhibition hall.

Nurses and staff in the Treatment Room.

The local volunteers outside the Palais des Congrès.
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www.ehc2012.eu

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www.hemophilia.org

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www.worldaidsday.org

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