



Message from the Medical Advisory Board Chair

Dr. Paul Giangrande, VP Medical and Chair, Medical Advisory Board

I am pleased to present highlights from the Medical Advisory Board (MAB) meeting held in Montreal on September 23, 2007.

Inhibitor risk

Recognizing that the threat of the development of inhibitors remains a potential and serious complication for patients with hemophilia, the WFH has established an Inhibitors Working Group. The working group will support a key objective of the WFH strategic plan, to “monitor research and treatment advances relative to adverse events (inhibitors, HIV, HCV) and provide timely information on their prevention, treatment and management.”

Inhibitor development has replaced pathogen risk as the most common adverse event for patients with severe hemophilia A. The risk of inhibitor development was a key topic at the WFH’s Fifth Global Forum on the Safety and Supply of Treatment

Products for Bleeding Disorders last September and the latest research findings will be presented at the upcoming WFH world congress in Istanbul this June.

There are many unanswered research questions about inhibitors and some controversy about possible predisposing risk factors. Precise information from the WFH to the bleeding disorders community on inhibitors is needed, communicating both the risk and its context relative to other factors such as supply, viral safety, efficacy, and price.

Dr. Keith Hoots (U.S.) was appointed chair of the working group, with committee members comprising experts from around the world. In 2008, the Inhibitors Working Group’s focus will be to help the WFH develop educational materials for clinicians and patients on risk of inhibitor development and treatment strategies.

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WFH launches newsletter for comprehensive care team

Welcome to the inaugural edition of the *WFH Medical Advisory Board News*, a multi-disciplinary newsletter for healthcare practitioners in the bleeding disorders field.

The WFH Medical Advisory Board (MAB) has been an important part of the World Federation of Hemophilia (WFH) since its beginnings 45 years ago, but the MAB was reorganized last year to incorporate membership from the entire comprehensive care team. Members include medical members of the WFH Executive Committee, chairs of WFH multi-disciplinary advisory committees

(Musculoskeletal, Laboratory Sciences, Nurses, Dental, and Psychosocial), the WFH Blood Safety Advisor, and chairs of the International Hemophilia Training Centre, Gene Therapy and Novel Technologies, and Von Willebrand Disease & Rare Bleeding Disorders committees.

Under the direction of the Vice-President Medical, the MAB

- Provides oversight, advice, and expertise regarding key medical and clinical issues;
- Promotes new developments in treatment, care, and medical research on a global level;

- Advises on policy, guidelines, and position statements on particular aspects of treatment of bleeding disorders; and
- Ensures coordination and information sharing on all medical activities of the WFH.

As part of the MAB reorganization, this newsletter has been developed to help share information about WFH multidisciplinary activities, promote the comprehensive care model, and foster integration among disciplines.

We hope you enjoy reading it, and welcome your feedback.

WFH-WHO joint meeting planned on comprehensive care

At the September meeting, the Medical Advisory Board also selected “models of comprehensive care” as the topic for a joint meeting with the World Health Organization (WHO) planned for 2009. The WFH has developed a highly successful model for building comprehensive and sustainable treatment for people with congenital bleeding disorders in countries where there are limited resources. However, a comprehensive care model is as important in countries where treatment is well established. Given tremendous competition for public health funding, there needs to be continued advocacy to protect comprehensive care for hemophilia against pressures to decrease government funding for high-cost/low-

volume diseases.

In practice, the organization of comprehensive care and multidisciplinary teams vary greatly from country to country. The joint WHO-WFH meeting in 2009 would work towards defining different models of comprehensive care optimal in different economic and healthcare system contexts.

The WFH is developing a discussion paper on comprehensive care models to begin the collaborative effort with WHO, which has already expressed interest in this topic. Past joint WHO-WFH meetings have focused on prevention and control of hemophilia, delivery of treatment of hemophilia, hemophilia care in developing countries, and modern treatment of hemophilia.

Multidisciplinary activities update

WFH Multidisciplinary committees represent various members of the comprehensive care team and promote improved care for people with hemophilia and other inherited bleeding disorders. Here is a summary of some of the past accomplishments and ongoing projects of our multidisciplinary committees. The next four months will be busy as committee volunteers work hard to ensure a first-rate scientific program for the world congress in Istanbul this June.

Musculoskeletal Committee

Kathy Mulder (Canada), Chair

The Musculoskeletal (MSK) Committee had an outstanding year in 2007, with the largest-ever WFH MSK Congress held in Italy in May, a global campaign for World Hemophilia Day on the importance of exercise and physical therapy in hemophilia care, and the publication of the illustrated guide, *Exercises for People with Hemophilia*, now available in English and Spanish. French, Russian, Arabic, and Chinese editions are also being developed.

In 2007, musculoskeletal workshops were held in Ecuador, the Middle East and eastern Europe, and a pilot of the Global Physiotherapy Initiative workshop was held in Egypt. The committee, through the efforts of Dr. Luigi Solimeno, is launching *The Orthopedic Book*, a comprehensive publication with full-colour images dedicated in memory of past committee

chair Dr. Henri Horoszowski. For more information contact www.springer.com.

Assessment tools under development

The need for hemophilia-specific assessment tools is great. Discussions are ongoing between the MSK Committee and the International Prophylaxis Study Group regarding the Hemophilia Joint Health Score (HJHS) and MRI scores that are being developed. The ultimate goal is to have the WFH adopt reliable, validated tools such as the HJHS, Hemophilia Activities List (HAL), Functional Independence Score for Hemophilia (FISH), and MRI scores as the “gold standards”. The Pettersson score is still valid for plain radiographs, while the IPSP MRI expert working group is also working on an ultrasound scale that would be more practical than MRI in many situations. Workshops regarding the application of the HJHS and the MRI scores are being developed for the world congress in June.

Congress preparations

Preparations are underway for World Congress in Istanbul. For 2009, Cartagena, Colombia, has been selected for the site of the next WFH Musculoskeletal Congress.

Nurses Committee

Lara Oyesiku (U.K.), Chair

The *Hemophilia in Pictures Educator's Guide* is being published at last, the result of two years' work by WFH healthcare volunteers from across the multi-disciplinary fields. The educator's guide is a companion to *Hemophilia in Pictures*, the WFH pictorial educational module developed by the WFH with the Nurses Committee. The educator's guide provides tools for teaching about hemophilia and comprehensive information on diagnosis and treatment, related complications (transfusion-transmitted diseases and inhibitor risk), and staying healthy.

The committee continues to update their registry of experienced hemophilia nurses who can be called upon for their expertise at WFH workshops or meetings. Please contact Lara Oyesiku if you have expertise in a particular field and would be willing to be involved in outreach programs. We continue to strive for greater nurse involvement in WFH workshops, which has brought greater focus on the role of the nurse specialist.

Building on a highly successful nurses workshop in southeastern Brazil last year, representatives of the

committee will be returning to Brazil this year to lead nursing symposia in other regions (see article below).

The Pre-congress Nurses workshop was a great success at the last WFH Congress in Vancouver, 2006, with a record attendance. We are currently busy organizing another educationally stimulating program which again will be a full day meeting. The congress committee is working hard to get CPD accreditation for this day.

Recruitment is ongoing for new committee members. There are currently four vacant positions: Eastern Europe, South East Asia, Africa, and the Western Pacific. Further positions will become vacant as several terms conclude at the congress this June, representing Western Europe, the U.K., and North America. The closing date for nominations was the 21st January. To date we have not received any applications from the South East Asia region. Anyone interested in applying for the South East Asia region may still submit their completed application and manifesto to Lara Oyesiku, details below. If you want to find out more about the Nurses Committee or any of the items mentioned here please contact Lara at: Lara.Oyesiku@orh.nhs.uk.

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Nurses symposium held in Brazil

Elizabeth A. Paradis, member, WFH Nurses Committee

The Brazilian Federation of Hemophilia held its second nurses symposium, titled Multi-Disciplinary Symposium in Hemophilia, last October in Brasilia, the capital of Brazil. Co-chaired by Dr. Sylvia Thomas and Anna Claudia Acerbi Vrabic, the symposium included 40 participants from the northern and northeastern regions of Brazil, 9 of whom were physicians. Speakers gave interactive and high quality presentations on a variety of topics, including: hemophilia basics, clinical and laboratory diagnosis, policy of treatment of hemophilia in Brazil, primary and secondary prophylaxis, management of bleeding episodes, inhibitors, von Willebrand disease, and rare coagulopathies. Four of the speakers were nurses from hemophilia centres in Sao Paulo and Rio de Janeiro who had attended the first workshop in 2007.

A psychologist spoke on the importance of the multidisciplinary team in the treatment of bleeding disorders. There was also a presentation by a physiotherapist on exercises for persons with bleeding disorders.



The symposium concluded with a session on hepatitis C by Dr. Cor Jesus, a specialist in infectious diseases, from the University of Porto Velho.

I was very honoured to have been a guest speaker at this symposium. I encouraged the nurses to write an abstract to present at the WFH congress in Istanbul, Turkey. They have written and submitted a wonderful abstract and three of the nurses are learning the English language.

A third symposium is planned for April 2008.

Hemophilia 2008 – World Congress in Istanbul, Turkey

In addition to a comprehensive scientific program at the WFH congress, there will be an extensive multidisciplinary program for different members of the comprehensive care team. Pre-congress multidisciplinary workshops will also be offered (see page 5 for details). For more information visit www.hemophilia2008.org.

Plenaries

- Advancements in management of viral hepatitis
- Back to the future: A history of the treatment of hemophilia
- Ethical issues relating to clinical research in hemophilia
- Experimental models of tissue bleeding and wound repair
- Quality of life in hemophilia
- The future of immunotherapy for FVIII inhibitors
- The role of synovectomy in the management of a target joint
- WFH – The cornerstone of global development – 45 years in progress

Dental

- Management of trauma
- Restorative dentistry
- Surgery and extractions

Laboratory

- External quality assessment schemes
- Genetic aspects and research developments in hemostasis
- Laboratory issues in bleeding disorders
- New approaches in the measurement of coagulation

Medical

- Acquired hemophilia and VWD
- Advancements in imaging
- Challenges in laboratory diagnosis
- Hemophilia in the first years of life
- Infectious diseases
- Inhibitors management
- Linking the world with training and research for improving hemophilia care
- Management of carriers and babies with hemophilia
- Mild/moderate hemophilia A: New insights on molecular mechanisms and inhibitor development
- Progress in molecular biology of inherited bleeding disorders
- Prophylaxis: Current status and future challenges

- Rare bleeding disorders
- Relevance of quantitative assessment of bleeding in hemorrhagic disorders
- VWD update: Diagnostic and treatment dilemmas

Multidisciplinary

- Being heard without screaming: The role of media
- Did anyone ask the siblings?
- Educational models in hemophilia care: A worldwide overview of existing models
- Emergency preparedness: Lessons for the global bleeding disorders community
- Going beyond: Models to promote education, training, and employment
- Habitat for hemophiliacs: How to create better living spaces for people with bleeding disorders
- How elderly people with bleeding disorders manage their condition
- Impact of WFH twinning programs
- Innovations in factor therapies for people with bleeding disorders
- Life stages: Childhood and adolescence
- Limited resources, unlimited efforts: healthcare models in developing countries
- Psychosocial impacts of limits to physical activity and sports in people with bleeding disorders
- Quality of life in patients with inhibitors
- Scarce resources, difficult choices
- Sharing a hard life: How hemophilia affects the family
- Twenty-five years later: HCV/HIV issues in the hemophilia community
- Von Willebrand disease: Issues for women and men
- Women and hemophilia

Musculoskeletal

- International Prophylaxis Study Group final report
- Physical activity in boys with hemophilia: A multicentre study
- Role of the physiatrist
- Surgical options for the ankle: Pros and cons

Pre-congress workshops

These workshops take place on Sunday, June 1, and are free for those who have registered for the WFH congress. Registration is on a first come, first served basis and space is limited, so register early. You can register online at www.hemophilia2008.org, or if you have already registered for the congress, email your choice to hemophilia2008@wfh.org.

08:30 – 16:30 Nurses Workshop

Chairperson: Lara Oyesiku

This workshop is designed to assist nurses of all levels of practice to work as part of a multidisciplinary healthcare team. The workshop will include a plenary on advanced nurse practice relating to hemophilia nursing and sessions on “Advancing hemophilia nursing one step forward...” by Martin Bedford and “Genetics in Practice” by Diane Marshall. The use of theatre as a medium for imparting educational information will be included along with other varied topics throughout the day, some of which will touch on issues relating to the various life stages: advanced years, adulthood, adolescence, and childhood.

08:30 – 16:30 Psychosocial Workshop

Chairpersons: Richa Mohan and Ruud Bos

Plans are well underway for another excellent pre-congress day program. The full-day workshop will include sessions on the role of the social worker and the psychologist in comprehensive hemophilia care, research methods, counseling, empowering parents, clinical case presentation, and promoting hardiness.

08:30 – 16:30 Physiotherapy Workshop

Chairperson: Kathy Mulder

This workshop will include a session on the hemophilia joint health score assessment form. Other topics include physical therapy standards, the role of physical therapy in WFH twinning projects, and educational materials on physical therapy for people with hemophilia.

08:30 – 16:30 Orthopedics Instructional Course

Chairpersons: Adolfo Llinás and Pier Solimeno

This workshop will include sessions on imaging, arthroplasty registry, case reports, and development of evidence-based surgical guidelines.

13:30 – 16:30 Coagulation Workshop

Chairperson: Angus McCraw

This half-day workshop is intended for laboratory technologists, clinical pathologists, and clinicians with an interest in diagnosis. The session will feature discussions on semi- and fully automated systems and comparison of technology.

Laboratory instrumentation and analyser companies will be invited to showcase and demonstrate their equipment.

13:30 – 16:30 Women’s Outreach Strategies Workshop

Chairpersons: Ann-Marie Nazzaro and Clare Cecchini

This new half-day workshop is targeted to national hemophilia organization representatives, those responsible for programming/services/outreach, women with and/or affected by bleeding disorders, and healthcare professionals. The workshop will brainstorm (in small groups) on country- and region-appropriate outreach strategies for disseminating information on women’s bleeding disorders, as well as panel discussions showcasing various outreach strategies from different countries/cultures, including both fledgling efforts at education and outreach to women and best practice models of successful outreach to women.

15:00 – 16:30 Gene Therapy Workshop

Chairperson: David Lillicrap

New this year, this workshop will give a brief overview of gene therapy, as well as discuss gene delivery systems and gene therapy challenges. Targeted to clinicians, laboratory scientists, and other healthcare professionals, this session will focus on the preclinical background, clinical trails, and innovative approaches to hemophilia gene therapy.

Multidisciplinary activities update (cont'd from page 3)

Dental Committee

Andrew Brewer (U.K.), Chair

The Dental Committee is developing a monograph on the treatment of hemophilia patients with inhibitors to factor VIII and IX, a follow-up to the dental treatment guidelines the committee published in 2006. This will be published in time for the WFH congress.

A dental data collection form is being devised for clinicians, also to be launched at the world congress. While it will be impossible to fully standardize dental examinations in the absence of formal training sessions, the aim of this initiative is to obtain the first real snapshot of the dental status of patients with hemophilia on a worldwide basis.

The Dental Committee is the smallest of the WFH healthcare committees and it is difficult to recruit members since dental treatment of patients with hemophilia is a minor area within the dental profession. We would like to become involved with training and interdisciplinary work and welcome any collaboration with the other committees. If you are interested in getting involved please contact Andrew Brewer at andrew.brewer@northglasgow.scot.nhs.uk

Psychosocial Committee

Maureen Spilsbury (Australia), Chair

There is keen interest among Psychosocial Committee members to explore quality of life research in the area of aging and inhibitors. Quality of life in hemophilia has developed as a discipline with utility measures and economic implications, and research could provide measurements about aging and inhibitors that are important in resource allocation.

The Psychosocial Committee hopes to hold another **Parents Empowering Parents workshop** in conjunction with the WFH pre-congress workshops in Istanbul in June. The one-day training course brings together social workers, nurses, and family members to learn about how to collectively build a supportive parenting program for families of children with hemophilia and other congenital bleeding disorders. The workshop focuses on building skills step by step. Topics covered include child development, building self-esteem, understanding and communication, and compassionate discipline. Check the WFH Congress website for registration details or contact Maureen Spilsbury by email.

We are also working to ensure that members can access funding to attend the congress and the important face-to-face committee meetings that take place during the congress.

The committee seeks to establish contact with psychosocial workers in Asia, Africa, and the

Middle East in order to learn about psychosocial issues and needs in these regions. Recognizing that there may be a lack of professional psychosocial workers in some countries, members agree that community members or other healthcare professionals positioned to provide hemophilia psychosocial support could be sought to gain insight and input from these regions. Anyone interested in this or other psychosocial committee issues can contact Maureen Spilsbury by email at maureen_spilsbury@health.qld.gov.au.

Laboratory Sciences Committee

Angus McCraw (U.K.), Chair

In 2007 the committee organized six national lab workshops (Philippines, Mexico, Brazil, Peru, Saudi Arabia, and Egypt), one regional workshop in Jordan, and one Training the Trainer workshop in London (see article on page 7).

The Laboratory Sciences Committee is currently working on a revised edition of *Diagnosis of Hemophilia and Other Bleeding Disorders: A Laboratory Manual*, originally published in 2000. The new edition will include both manual and semi-automated tests.

Call for committee member nominations

Members of WFH advisory committees are appointed every two years for a two-year term. New members will be appointed following the WFH Hemophilia 2008 World Congress. If you or one of your colleagues is interested in becoming involved in one of the following committees, please contact the WFH or a committee chair for more information.

Dental Committee

Contact: Andrew Brewer
andrew.brewer@northglasgow.scot.nhs.uk

Laboratory Sciences Committee

Contact: Angus McCraw
angus.mccraw@royalfree.nhs.uk

Musculoskeletal Committee

Contact: Kathy Mulder
kmulder@hsc.mb.ca

Nurses Committee

Contact: Lara Oyesiku
lara.oyesiku@orh.nhs.uk

Psychosocial Committee

Contact: Maureen Spilsbury
maureen_spilsbury@health.qld.gov.au

Sharing the knowledge: 3rd training the trainer lab workshop a success

Angus McCraw, Chair, Laboratory Sciences Committee



June 2007 saw the Royal Free Hospital, London hosting the third WFH Training the Trainer course. The course passes on skills and expertise to improve laboratory training. This year eight participants came from Sri Lanka, India, Brazil, Kenya, China, Uzbekistan, Belarus, and Russia and all were chosen by the WFH regional program managers as being the people who would most benefit from such training.

Learning how to present and teach about hemostasis and basic coagulation tests is the core focus of Training the Trainer but it is also a very hands-on course. Everyone has the opportunity to do basic screening tests, factor assays, and inhibitor detection and quantitation both manually and on semi-automated analysers. All this practical participation helps them learn different teaching methods and gives a real feel of what it is like to be on the other side of the laboratory bench.

As well as screening tests, the group learned more about laboratory facilities, sample preparation, and storage of reagents and their sensitivity, all of which are vital to a well-run laboratory, and everyone was able to swap experiences about their own situations and environment.

As with the previous courses there was much emphasis on internal quality control (IQC), external quality assessment (EQA), the use of reference plasmas with detailed discussion around the relationship of tests to international standards and the importance of the validity of results.

Significance was also given to standard operating procedures (SOP) and with a visit to the diagnostic laboratory of the hemophilia centre the group was able to see first-hand some of the other specialized tests that are routinely performed. It is hoped that this exposure to learning and sharing of ideas will all go towards a harmonization of coagulation laboratory practice around the world.

Having developed and organized the three Training the Trainer workshops, I know that the great success of this course is in the participants' enthusiasm and eagerness to learn, along with the reciprocal enthusiasm of the hemophilia centre laboratory staff. These workshops are a very effective way to help people who have limited access to resources, and it gives an excellent opportunity for staff from a well-developed hemophilia centre laboratory to share their skills and expertise in a very targeted way.

For more information about the Training the Trainer program, visit the WFH website at www.wfh.org.



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