Detailed program

Professional development workshops
Sunday, July 8, 2012
- Nurses workshop
- Psychosocial workshop
- Physiotherapy workshop
- Orthopedics workshop
- Laboratory Sciences workshop
- Women & Bleeding Disorders workshop
- Clinical Research workshop
- Publishing workshop
- Gene Therapy workshop

Congress sessions
- Monday, July 9, 2012
- Tuesday, July 10, 2012
- Wednesday, July 11, 2012
- Thursday, July 12, 2012
Professional development workshops
Sunday, July 8, 2012

NURSES WORKSHOP

09:15-15:00 (sponsored by Baxter)
Room: 241
Chair: Elizabeth Paradis, Canada

09:15
Introduction
Elizabeth Paradis, Canada

09:30
Ice breaker
WFH Nurses Committee

10:15
How to examine the knee and ankle
Anne Powell, Australia

10:45-11:00
Break

11:00
Hot topic
Patricia Guillon, France

11:25
Burnout
Karen Wulff, U.S.A.

12:15-13:15
Lunch

13:15
Developing an abstract/poster
Martin Bedford, U.K.

13:45
Free paper: Introducing nursing research: Improving hemophilia care by engaging nurses in clinical research
Kate Khair, U.K.

14:15
Nursing research
• Free paper: Are nurse education programs effective? Evaluation of a program offered in South Africa
  Jill Smith, Australia
• Nursing research
  Jessica Li, China
  Karin Lindvall, Sweden

14:55
Closing remarks
Jim Munn, U.S.A.

PSYCHOSOCIAL WORKSHOP

09:15-16:15
Room: 251
Co-chairs: Richa Mohan, India, and Ruud Bos, The Netherlands

09:15
Welcome and introduction
Ruud Bos, The Netherlands

09:45
Ice breaker exercises
Susan Cutter, U.S.A.

10:00
Session I
Chair: Richa Mohan, India
• Pain management
  Michelle Witkop, U.S.A.
  Angela Lambing, U.S.A.

10:45
Session II
Chair: Taheri Noorallah, Iran
• Risk reduction & harm prevention in sports
  Dawn von Mayrhauser, U.S.A.
  Laurel McKernan, U.S.A.
• Research in sports assessment
  Sylvia von Mackensen, Germany

LUNCH & SYMPOSIUM 12:00-13:30
Chair: Ruud Bos, The Netherlands
12:30
HERO results
Frederica Cassis, Brazil

13:30
Session III
Chair: Richa Mohan, India
- Impact of hemophilia on partners
  Anne Duffy, Ireland
  Anthony Roberts, South Africa

14:15
Session IV: Interactive workshop
Chair: Anne Duffy, Ireland
- Dealing with sexuality and intimacy in people with hemophilia
  Woet Gianotten, The Netherlands

15:30
Session V: Interactive group work
Chair: Richa Mohan, India
- Clinical case presentation and discussion
  Sylvia von Mackensen, Germany
  Irene Fuchs, Argentina

16:00
Closing remarks and evaluations
Ruud Bos, The Netherlands

PHYSIOTHERAPY WORKSHOP

09:30-14:00
Room: 343
Chair: Angela Forsyth, U.S.A.

09:30
Welcome and introduction
Angela Forsyth, U.S.A.

09:45
MSK report
Angela Forsyth, U.S.A.

10:15
Physiotherapy past, present, and future
Co-chairs: Kathy Mulder, Canada, and Pamela Narayan, India
- Past
  Brenda Buzzard, U.K.

- Present
  Natasa Jankovic, Serbia
- Future
  Klaus Osterholm, Finland

11:15-11:30
Break
11:30
Clinical topics
Chair: Sameer Rahim, South Africa
- Role of Taping in MSK Bleeding, Swelling, etc.
  Cindy Bailey, U.S.A.

12:00-13:00
Lunch

13:00
Research topics
Chair: Karen Beeton, U.K.
- Review of evidence-based practice
  Pattye Tobase, U.S.A.
- Research updates
  Audience discussion

13:45
Closing remarks
Angela Forsyth, U.S.A.

ORTHOPEDICS WORKSHOP

14:30-16:00
Room: 343
Chair: Pier Luigi Solimeno, Italy

14:30
Welcome and introduction
Pier Luigi Solimeno, Italy

14:40
Sports and hemophilia
Axel Seuser, Germany

15:25
Preliminary data of knee registry
Gianluigi Pasta, Italy

15:50
Closing remarks
Pier Luigi Solimeno, Italy
LABORATORY SCIENCES WORKSHOP

09:00-12:00
Lab Science: Pre-analytical variables and coagulometer evaluation
Room: 252AB
Co-chairs: Steve Kitchen, U.K., and Sukesh Nair, India

09:05
Sample collection including effects of anticoagulant and tube and sample preparation
Guiseppi Lippi, Italy

09:30
Sample storage and stability at different temperatures
Sukesh Nair, India

09:55
How do Hemolysis or under/overfilling samples affect hemostasis tests
Steve Kitchen, U.K.

10:20-10:40
Break

10:40
Reference ranges: What needs to be established locally and how should it be done?
Marion Echenagucia, Venezuela

11:05
How to select and evaluate coagulometers
Pierre Toulon, France

11:40
Pre-analytical variable effects: Case studies
Steve Kitchen, U.K.
Sukesh Nair, India

WOMEN & BLEEDING DISORDERS WORKSHOP

13:00-16:00
Room: 252AB
Chair: Rezan Kadir, U.K.

13:00
Multidisciplinary clinic for women with bleeding disorders
Rochelle Winikoff, Canada

13:15
Foundation for women and girls with blood disorders: The US experience
Ann-Marie Nazzaro, U.S.A.

13:30
Gynecological problems in women with bleeding disorders
Mans Edlund, Sweden

13:45
Prenatal diagnosis
Rezan Kadir, U.K.

14:00
Question and answer period

14:15-14:30
Break

14:30
Antenatal complications
Flora Peyvandi, Italy

14:45
Hemostatic agents in pregnancy
Augusto Federici, Italy

15:00
Management of labour and delivery
Ingrid Pabinger, Austria

15:15
Post-partum hemorrhage: How to predict, prevent, and manage
Andra James, U.S.A.

15:30
Case presentations
Debra Pollard, U.K.

15:45
Question and answer period
CLINICAL RESEARCH WORKSHOP

08:30-12:30
Room: 352AB
Co-chairs: Frits Rosendaal, The Netherlands and David Lillicrap, Canada

Speakers:
Anske van der Bom, The Netherlands
Flora Peyvandi, Italy
Alberto Tosetto, Italy

PUBLISHING WORKSHOP (WILEY-BLACKWELL)

13:30-15:00
Room: 352AB
Chair: Christine A. Lee, U.K.

The Haemophilia journal – historical review, outline, and geographical breakdown
Christine A. Lee, Editor, U.K.

How to write a scientific paper
Christine A. Lee, Editor, U.K.

The editorial process
Craig Kessler, Editor, U.S.A.

Plagiarism and how to avoid it
Michael Makris, Editor, U.K.

Publishing in the future
Samantha Gough, Journal Manager, U.K.

GENE THERAPY WORKSHOP

15:30-17:00
Room: 352AB
Chair: David Lillicrap, Canada

Basic components of a gene therapy protocol
David Lillicrap, Canada

Methods of gene delivery – pros and cons
Thierry Vandendriessche, Belgium

Organization of gene therapy clinical trials
Margareth Ozelo, Brazil
Congress sessions
Monday, July 9, 2012

INDUSTRY SYMPOSIA 07:00-08:30

CONCURRENT SESSIONS 08:45-10:15

S-MO-01.1 – MEDICAL

Trial updates and standardization issues
Room: Grand Amphitheatre
Chair: Alok Srivastava, India
- Results from the Rodin study
  Marijke Vandenberg, The Netherlands (TBC)
- Exposure date data
  Nisha Jain, U.S.A. (TBC)
- MUSFIH study
  Alok Srivastava, India
- Potency labels of clotting concentrates
  Tony Hubbard, U.K.

FP-MO-01.1 – MEDICAL

Free papers 1: Clinical issues
Room: 352AB
Chair: Andra James, U.S.A. (TBC)
- Efficacy and safety of B-domain deleted recombinant porcine factor VIII (OBI-1) in the treatment of acquired hemophilia A: Interim results
  Edward Gomperts, U.S.A
- Acute coronary syndromes in persons with hemophilia – comments on ESC guidelines by the ADVANCE working group
  Peter Staritz, Germany
- The prevalence of hypertension in hemophilia – a single centre experience
  Annette Von Dygalski, U.S.A.
- Tosetto Bleeding Score and factor VIII or IX levels in hemophilia carriers
  Femke Van Herrewegen, The Netherlands
- Low factor VIII is associated with bleeding during early pregnancy
  Andra James, U.S.A. (TBC)
- The prevalence of disorders of hemostasis in adolescent girls with menorrhagia
  Silvia Linari, Italy

S-MO-01.3 – MUSCULOSKELETAL

Consequences of intra-articular bleeding in hemophilia: Science to clinical practice and beyond
Room: Bordeaux Amphitheatre

Co-chairs: Angela Forsyth, U.S.A. and Georges Rivard, Canada
- Inflammation
  Paul Monahan, U.S.A.
- Wound healing in bleeding disorders
  Maureen Hoffman, U.S.A.
- Translation of results from animal cartilage to human cartilage
  Monique van Meegeren, The Netherlands
- Synovium
  Len Valentino, U.S.A.
- Bone defects (tissue engineering)
  Francesco Forriol, Spain
- The use of ice in acute bleeding
  Nichan Zourikian, Canada

S-MO-01.4 – NURSE

RBD: Familiar name, rare disorder
Room: Salle Maillot
Chair: Kate Khair, U.K.
- Resources
  Jennifer Maahs, U.S.A.
- Cultural/ethical sensitivity
  Mahmoud Ibrahim Abu Riash, Saudi Arabia
- Treatment/case studies
  Anu Laul, Estonia
- Free paper: Pregnancy and successful delivery of patients with FXIII deficiency on prophylaxis in Iran; report of 17 cases
  Majid Naderi, Iran

S-MO-01.2 – MULTIDISCIPLINARY

HCV/HIV Setbacks and Advancements
Room: 252AB
Chair: Jan Kuhn, U.S.A.
- Integrating healthcare professionals and patients
  Maria Virginia Puglia, Italy
- Clinical advancements: Promoting health and minimizing side effects
  Jan Kuhn, U.S.A.
- Psychological aspects in patients with HIV, HCV and hemophilia
  Dominique Magli-Barioz, France
- Effect on family, friends, and work
  Masood Malik, Pakistan
- A shared decision
  Neil Boal, Australia

S-MO-01.5 – PSYCHOSOCIAL

Adherence
Room: 251
Chair: Susan Cutter, U.S.A.
Influence of patient education on adherence: Is teaching enough?
Regina Butler, U.S.A.

Cultural views and approaches to adherence
Susan Cutter, U.S.A.

Youth adherence study results
Sylvia von Mackensen, Germany

10:15-10:45
Refreshment Break

PLENARY SESSIONS 10:45-12:15

PL-MO-02.1 – PLENARY 01
Room: Grand Amphitheatre
Chair: Alison Street, Australia
- WFH president's address: Closing the global gap – achieving optimal care
  Mark W. Skinner, U.S.A.

PL-MO-02.2 – PLENARY 02
Room: Grand Amphitheatre
Chair: Alison Street, Australia
- New approaches/horizons to the management of hepatitis C in hemophilia in 2012
  Fabien Zoulim, France

LUNCH BREAK & INDUSTRY SYMPOSIA
12:15-14:15
Lunch break and industry symposia

CONCURRENT SESSIONS 14:15-15:45

S-MO-03.1 – MEDICAL
Von Willebrand disease biology
Room: Grand Amphitheatre
Chair: David Lillicrap, Canada
- Personal reflections on the discovery and the clarification of Von Willebrand disease
  Margareta Blomback, Sweden
- Weibel-Palade body formation
  Jeroen Eikenboom, The Netherlands
- ADAMTS13 cleavage of VWF
  David Lane, U.K.
- Mouse models of VWD
  Cecile Denis, France

Co-chairs: Nicholas Goddard, U.K., and Monique van Meegeren, The Netherlands
- Using the Haemophilia Joint Health Score (HJHS) in adult patients: Testing inter-rater reliability
  Kathelijn Fischer, The Netherlands
- The potential role of synovial thrombomodulin in the pathophysiology of joint bleeds in hemophilia
  Yesim Dargaud, France (TBC)
- Pseudotumor surgery in Hemophilia A patients: Comparative results between inhibitor and non-inhibitor patients
  Horacio Caviglia, Argentina
- Arthroscopic ankle arthrodesis for hemophilic arthropathy
  Yusuke Inagaki, Japan
- Compartment syndrome in patients with inhibitors
  Nicholas Goddard, U.K.
- 186Re radiosynovectomy for chronic synovitis in children with hemophilia
  Pawel Laguna, Poland (TBC)

FP-MO-03.2 – MEDICAL
Free papers 2: Product and clinical trials 1
Room: 241
Chair: Christopher Ludlam, U.K.
- Pro-coagulant peptides as potential novel therapeutics for FVIII deficiency
  Karina Thorn, U.S.A.
- Enhancing the pharmacokinetic properties of recombinant factor VIII: A first human dose trial with glycoPEGylated recombinant factor VIII in patients with hemophilia A
  Andreas Tiede, Germany (TBC)
- An open-label phase I study to evaluate the pharmacokinetics and safety profile of BAY 94-9027, a PEGylated B-Domain – deleted recombinant factor VIII, in previously treated patients with severe hemophilia A
  Thomas Coyle, U.S.A.
- Safety of polyethylene glycol (PEG) in biopharmaceuticals: Focus on PEG-rFVIII
  Peter Turecek, Austria
- Does PEGylated factor VIII induce antibodies against PEG?
  Birgit M. Reipert, Austria
- Results of a phase I international clinical trial of recombinant fusion protein linking coagulation factor IX with albumin (rIX-FP) in patients with hemophilia B (PROLONG-9FP)
  Elena Santagostino, Italy

FP-MO-03.3 – MUSCULOSKELETAL
Free papers 1
Room: 352AB
S-MO-03.4 – MULTIDISCIPLINARY

Practical tips for (re)-discovering movement
Room: 252AB
Chair: Angela Forsyth, U.S.A.
  • Making good use of the body
    Michel Raymond, France
  • Bringing movement back into daily lives
    Sameer Rahim, South Africa
  • Home adaptations and devices to help with movement: Examples from established countries
    Klaus Osterholm, Finland
  • Home adaptations and devices to help with movement: Examples from emerging countries
    Marcia Matta, Brazil

S-MO-03.3 – MULTIDISCIPLINARY

Debate: Seeing both sides
Room: Salle Maillot
Chair: Rob Christie, Australia
  • Prophylaxis team A
    Brian O’Mahony, Ireland
    Jan Astermark, Sweden
  • Prophylaxis team B
    David Page, Canada
    Paul Giangrande, U.K.
  • Comprehensive care/guidelines team A
    Mark W. Skinner, U.S.A.
    Alok Srivastava, India
  • Comprehensive care/guidelines team B
    Dean York, New Zealand
    Alison Street, Australia

S-MO-03.2 – MULTIDISCIPLINARY

Outreach methodology: Hemophilia
Room: 251
Chair: Paula Bolton-Maggs, U.K.
  • Example from Thailand
    Jurarat Suriyathai, Thailand
  • Example from Mexico
    Marta Monteros Rincón, Mexico
  • Example from Egypt
    Nadia Moharram, Egypt
  • Example from Belarus
    Siarhei Misevich, Belarus

S-MO-04.1 – MEDICAL

Treatment of human immunodeficiency virus and hepatitis B virus infections
Room: Grand Amphitheatre
Chair: Christopher Ludlam, U.K.
  • HIV treatments – state of the art
    Margaret Johnson, U.K.
  • HBV Treatments – state of the art
    Fabien Zoulim, France
  • Accelerated access
    Craig Kessler, U.S.A.

S-MO-04.6 – LABORATORY SCIENCES

Global hemostasis & point of care testing
Room: 352AB
Co-chairs: Alok Srivastava, India, and Claude Negrier, France
  • Thrombin generation in bleeding disorders: Current state of the art
    Yesim Dargaud, France
  • How to perform and use ROTEM testing in bleeding disorder investigations
    Benny Sorensen, U.K.
  • Clot waveform analysis: Does it have a role?
    Midori Shima, Japan
  • Diagnostic usefulness of adenosine triphosphate release assays and aggregation tests with native or platelet count adjusted platelet rich plasma
    Catherine Hayward, Canada

S-MO-04.2 – MULTIDISCIPLINARY

Hot topics
Room: Bordeaux Amphitheatre

S-MO-04.3 – MULTIDISCIPLINARY

The economics of hemophilia care
Room: 252AB
Chair: Declan Noone, Ireland
  • Rationale of registries and data collection
    Angelika Batorova, Slovak Republic
  • The economics of hemophilia care in mexico
    Ricardo Carlos Gaitan-Fitch, Mexico
  • Pioneering health technology assessments of hemophilia care – sharing the Swedish experience
    Daniel Arnberg, Sweden
  • An economist's perspective
    Keith Tolley, U.K.

S-MO-04.4 – MULTIDISCIPLINARY

Women and bleeding disorders
Room: Salle Maillot
Chair: Elizabeth Paradis, Canada

REFRESHMENT BREAK & POSTER VIEWING
15:45-16:30

CONCURRENT SESSIONS 16:30-18:00
• Identification and detection of carriers of hemophilia
  Paul Giangrande, U.K.
• Experiences of carriers of hemophilia: Established country perspective
  Debra Pollard, U.K.
• Experiences of carriers of hemophilia: Emerging country perspective
  Shirin Ravanbod, Iran
• Pre-conception counselling: No one size fits all!
  Claire McLintock, New Zealand
• Reproductive choices
  Rezan Kadir, U.K.
• Management of pregnancy and delivery: What to expect when expecting
  Peter Kouides, U.S.A.

• Complications of hemophilia in children in the first two years of life: A report from the Centers for Disease Control (CDC) Universal Data Collection (UDC) system
  Michael Soucie, U.S.A.
• Web-based HTC-databases on a national scale – an integrated, effective & data-secure, nurse-led system on providing data for studies, information, and low cost treatment
  Wolfgang Balliel, The Netherlands

S-MO-04.5 – WFH
International Hemophilia Training Centres: The fellowship experience
Room: 251
Chair: Keith Hoots, U.S.A.
  • International Hemophilia Training Centre perspective
    Vikram Mathews, India
  • Nurse’s perspective
    Mahmoud Ibrahim Abu Riash, Saudi Arabia
  • Hematologist’s perspective
    Chean Sophal, Cambodia
  • Hematologist’s perspective
    Alessandra Nunes Loureiro Prezotti, Brazil
  • Physiotherapist’s perspective
    Natasa Jankovic, Serbia

FP-MO-04.4 – MEDICAL
Free papers 3: Clinical aspects, including registries
Room: Bordeaux Amphitheatre
Chair: Paula Bolton-Maggs, U.K.
  • Clinical presentation and management of adult patients responding to the Haemophilia Experiences Results Opportunities (HERO) study
    Alfonso Iorio, Canada
  • Age at the first bleeding could be a predictor of hemorrhagic phenotype in patients with severe hemophilia
    Chantal Rothschild, France
  • Adherence to prophylaxis in The Netherlands: A multicentre study
    Liesbeth Schrijvers, The Netherlands
  • Prophylaxis Versus On-demand Therapy Through Economic Report (P.O.T.T.E.R.) study: Preliminary data from the final 5 years analysis
    Annarita Tagliaferri, Italy
Congress sessions
Tuesday, July 10, 2012

INDUSTRY SYMPOSIA 07:00-08:30

CONCURRENT SESSIONS 08:45-10:15

S-TU-01.1 – MEDICAL

Rare bleeding disorders
Room: Grand Amphitheatre
Chair: Flora Peyvandi, Italy
- FXI
Paula Bolton-Maggs, U.K.
- FVII
Angelika Batorova, Slovak Republic
- Congenital fibrinogen disorders
Philippe de Moerloose, Switzerland

FP-TU-01.1 – MEDICAL

Free papers 4: Product and clinical trials 2
Room: Bordeaux Amphitheatre
Chair: Magdy El Ekiaby, Egypt
- An engineered "super" factor Va mutant as a potential bypassing agent in hemophilia
Annette Von Drygalski, U.S.A.
- Recombinant FVIIa-XTEN as a long-lasting form of rFVIIa with an enhanced PK profile
Susan Dallabrida, U.S.A. (TBC)
- One year clinical experience with solvent/detergent-filtered (SD-F) cryoprecipitate
Magdy El Ekiaby, Egypt
- Enhanced phosphorylation and sulfation of human recombinant factor IX for production by the hepatoma cell line HuH-7
Nathalie Enjolras, France
- Patients with hemophilia A and B have increased platelet TFPI
Paul Ellery, U.S.A.
- GlycoPEGylated rFVIII (N8-GP) has prolonged hemostatic effect in hemophilia A mice
Torben Elm, Denmark

FP-TU-01.2 – MUSCULOSKELETAL

Free papers II
Room: 352AB
- Physical activity measured by high-frequency accelerometry in boys with hemophilia
Cecily Bos, Canada
- Risk of bleeds associated with physical activity in children with hemophilia
Carolyn Broderick, Australia
- Endurance performance in adult hemophilia patients before and after a three-month sports therapy program: a randomized controlled trial (RCT)
Dorte Czepa, Germany
- Aerobic capacity in Egyptian adults with hemophilia
Howida Fouda, Egypt (TBC)
- Development of physical therapy practice guidelines for persons with bleeding disorders – outreach to community providers
Marc Gilgannon, U.S.A.
- Ambidexterity training program for patients with hemophilia
Margareth Ozelo, Brazil

S-TU-01.2 – MULTIDISCIPLINARY

Assessing quality of life in patients with bleeding disorders
Room: Salle Maillot
Chair: Sylvia von Mackensen, Germany
- Quality of life
Sylvia von Mackensen, Germany
- Healthcare utilization and cost of care: Insights from the Hemophilia Utilization Group Study (HUGS)
Kathleen A. Johnson, U.S.A.
- Optimizing treatment
Kathelijn Fischer, The Netherlands

S-TU-01.3 – MULTIDISCIPLINARY

Youth: Preparing future generations
Room: 252AB
Chair: Dorothée Pradines, France
- Feed forward: Preparing the next generation for governing your NMO
Deon York, New Zealand
- Keeping youth involved
David Pouliot, Canada
- Youth programs and concepts from an emerging country
Diego Gavidia Huanay, Peru
- Youth programs and concepts from an established country
Dorothée Pradines, France

S-TU-01.4 – NURSE

Hemophilia nursing in the surgical setting
Room: 251
Chair: Mary Brasser, New Zealand
- Tattoos and piercings
Mary Brasser, New Zealand
Free paper: Experience of circumcision using low quantities of factor concentrates
Moussa Seck, Senegal

Developing minimal factor use scenarios
Indu Mariya, India (TBC)

Free paper
TBD

10:15-10:45
Refreshment break

PLENARY SESSIONS 10:45-12:15

PL-TU-02.1 – PLENARY 03
Room: Grand Amphitheatre
Chair: Alok Srivastava, India
• Implementing musculoskeletal outcome assessments in clinical practice
  Brian Feldman, Canada

PL-TU-02.2 – PLENARY 04
Room: Grand Amphitheatre
Chair: Alok Srivastava, India
• Personalized prophylaxis
  Peter Collins, U.K.

LUNCH BREAK & INDUSTRY SYMPOSIA
12:15-14:15

CONCURRENT SESSIONS 14:15-15:45

S-TU-03.1 – MEDICAL
Models of prophylaxis
Room: Bordeaux Amphitheatre
Chair: Erik Berntorp, Sweden
• History of prophylaxis - Arosenius lecture
  Erik Berntorp, Sweden
• Swedish/Dutch comparison
  Kathelijn Fischer, The Netherlands
• Economic justifications of prophylaxis
  Alec Miners, U.K.

S-TU-03.6 – MEDICAL
Outcome assessment and limitations
Room: 352AB
Chair: Brian Feldman, Canada
• Clinical assessment of MSK outcome
  Pradeep Poonoose, India
• Radiological assessment
  Nidugala Keshava Shyamkumar, India

S-TU-03.4 – DENTAL
MTE: Challenges of an ageing population
Room: 343
Chair: Alison Dougall, Ireland
• Dentist perspective
  Andrew Brewer, U.K.
• Hematologist perspective
  Magdy El Ekiaby, Egypt
• Nurse perspective
  Lara Oyesiku, U.K.
• Social worker perspective
  Dawn von Mayrhauser, U.S.A.

S-TU-03.2 – MULTIDISCIPLINARY
Global models of pain management
Room: Salle Maillot
Chair: Pamela Narayan, India
• Overview: What is pain
  Michelle Witkop, U.S.A.
• Physiotherapy from an emerging country
  Pamela Narayan, India
• Music therapy as a Complementary and Alternative Medicine (CAM) technique
  Raffi Tachdjian, U.S.A.
• Creative visualization and movement
  Irene Fuchs, Argentina

S-TU-03.3 – MULTIDISCIPLINARY
E-communications: Benefits and pitfalls
Room: 252AB
Chair: Ahmed Al Qallaf, Kuwait
• E-communications to patients for patients
  Ahmed Al Qallaf, Kuwait
• Patient and family blogs
  Cheryl d’Ambrosio, U.S.A.
• Internet social network, our new communication breakthrough
  Antonius Ari Sudana, Indonesia
• E-communications for lobbying
  Dan Farthing, U.K.

S-TU-03.5 – PSYCHOSOCIAL
Ethical issues
Room: 251
Co-chairs: Anne Duffy, Ireland, and Ed Kuebler, U.S.A.
• Ethical issues in clinical trial participation
  Madeline Cantini, U.S.A.
• Ethical issues in hemophilia
  Maureen Spilsbury, Australia
• Code of practice  
  Ed Kuebler, U.S.A.  
• Disclosure issues in hemophilia care  
  Anthony Roberts, South Africa

REFRESHMENT BREAK & POSTER VIEWING  
15:45-16:30

CONCURRENT SESSIONS 16:30-18:00

LB-TU-04.1 – MEDICAL
Late-breaking session I  
Room: Bordeaux Amphitheatre  
Chair: Nigel Key, U.S.A.

FP-TU-04.3 – MEDICAL
Free papers 5: Clinical, including VWD and RBD  
Room: 352AB  
Chair: Kathelijn Fischer, The Netherlands (TBC)  
- A new class of mutations in the A3 region of von Willebrand factor inducing multiple functional defects in the protein  
  Olivier Christophe, France (TBC)  
- Pharmacokinetics, safety, and efficacy of a high purity factor X in patients with severe and moderate hereditary factor X deficiency  
  Miranda Norton, U.K.  
- Modelling life-long hemophilia treatment: Dose and discontinuation  
  Kathelijn Fischer, The Netherlands  
- Generation and optimization of the Self-Administered Bleeding Assessment Tool (Self-BAT)  
  Meghan de Forest, Canada  
- Patients with inhibitors  
  Nicholas Goddard, U.K.  
- ADAMTS13 cleavage of recombinant human Willebrand factor in severe VWD patients  
  Peter Turecek, Austria

S-TU-04.1 – LABORATORY SCIENCES
Difficulties and pitfalls in the laboratory diagnosis of bleeding disorders  
Room: 343  
- Introduction: Historical perspective  
  Andreas Hillarp, Sweden  
- Laboratory diagnosis of VWD: Role of VWF activity assays with and without ristocetin  
  Andreas Hillarp, Sweden  
- Laboratory diagnosis of VWD: Role of collagen binding assays in the diagnosis of VWD  
  Emmanuel Favaloro, Australia  
- Diagnosis of FXIII deficiency  
  Hans-P Kohler, Switzerland  
- WFH External Quality Assessment (EQA) program  
  Ian Jennings, U.K.

S-TU-04.2 – MULTIDISCIPLINARY
Hemophilia outreach and research: Experience from Africa  
Room: Salle Maillot  
Chair: Johnny Mahlangu, South Africa  
- Medical and Lay cooperation: A key strategy to implement hemophilia care program in Africa  
  Mohamed Yassine, Senegal, and Saliou Diop, Senegal  
- Research and ethical aspects of clinical trials  
  Johnny Mahlangu, South Africa  
- General outreach: The Kenya experience  
  Fatimah Abdollah, Kenya  
- VWD outreach  
  Magdy El Ekiaby, Egypt

S-TU-04.3 – MULTIDISCIPLINARY
Psychosocial models in hemophilia: Designs around the world  
Room: 252AB  
Chair: Anne Duffy, Ireland  
- Psychological approach in a hemophilia centre, Brazil  
  Frederica Cassis, Brazil  
- Model from The Philippines – HAPLOS  
  John Francis Sarmenta, The Philippines  
- Psychosocial models of care in Australia: Risky business?  
  Maureen Spilsbury, Australia

FP-TU-04.4 – MUSCULOSKELETAL
Free papers III  
Room: 251  
Co-chairs: Axel Seuser, Germany, and Sebastien Lobet, Belgium  
- Ankle fusion in patients with hemophilia  
  Benjamin Bluth, U.S.A. (TBC)  
- Association of hemophilic arthropathy with genetic markers related to bleeding tendency, joint inflammation, and structural cartilage  
  Ana Jaloma, Mexico  
- A population-based longitudinal study of musculoskeletal disorders in people with hemophilia, and their matched controls  
  Mohammed Khawaji, Sweden
• IL-6 receptor antagonist as adjunctive therapy for the prevention and treatment of bleeding-induced arthropathy
  
  Paul E. Monahan, U.S.A.

• Plasmin-induced proteoglycan release in human cartilage is PAR-dependent
  
  Laurens Nieuwenhuizen, The Netherlands

• A diagnostic, cross-sectional evaluation of joint status using magnetic resonance imaging in patients with severe hemophilia A treated with prophylaxis versus on-demand therapy
  
  Johannes Oldenburg, Germany

CULTURAL EVENT 18:00-20:00
Congress sessions
Wednesday, July 11, 2012

INDUSTRY SYMPOSIA 07:00-08:30

CONCURRENT SESSIONS 08:45-10:15

S-WE-01.1 – MEDICAL

Inherited platelet disorders
Room: Grand Amphitheatre
Chair: Alan Nurden, France
- Molecular basis
  Alan Nurden, France
- Diagnosis
  Kathleen Freson, Belgium
- Treatment
  Uri Seligsohn, Israel

FP-WE-01.1 – MEDICAL

Free papers 6: Inhibitors 1
Room: 352AB
Chair: Michael Makris, U.K.
- Polymorphism 131R>H in the FCGR2A gene is associated with inhibitor development in hemophilia A
  Corien Eckhardt, The Netherlands
- The change of serum BAFF level in the development of anti-factor VIII antibodies in hemophilia A mice
  Shin-Nan Cheng, Taiwan (TBC)
- Source and purity of factor VIII products as risk factors for inhibitor development in previously untreated patients with severe hemophilia A
  Maria Elisa Mancuso, Italy
- FVIII specific CD4+ T cell epitopes that drive immune responses to human FVIII in humanized HLA-DRB1*1501 transgenic hemophilic mice bind to multiple human HLA-DRB1* proteins
  Katharina Steinitz, Austria
- Non-neutralizing antibodies and the impact on thrombin generation in haemophilia A patients – Results from the MIBS and HIGS cohorts
  Jenny Klintman, Sweden
- Inhibitor incidence in PUPs and PTPs – data from the first 3 years of the EUHASS project
  Michael Makris, U.K.

S-WE-01.4 – MUSCULOSKELETAL

Musculoskeletal problems in persons with inhibitors: How do we treat?
Room: Bordeaux Amphitheatre

Co-chairs: Horacio Caviglia, Argentina, and Pamela Narayan, India
- Treating a patient with no factor available
  Sameer Rahim, South Africa
- In the middle – conservative management before EOS
  Kathy Mulder, Canada
- Physiotherapy and EOS review
  Angela Forsyth, U.S.A.
- Orthopedic surgery in INHs: The results and report from different series
  Nicholas Goddard, U.K.
- Hematology update
  Paul Giangrande, U.K.
- The ethics and economics of inhibitor surgery
  Marvin Gilbert, U.S.A.

S-WE-01.2 – MULTIDISCIPLINARY

Women’s voices
Room: Salle Maillot
Chair: Maureen Spilsbury, Australia
- The voice of comfort and promise
  Murielle Pradines, France
- Patient’s perspective
  Baiba M. Ziemele, Latvia
- Physician and patient
  Shahla Sohail, Pakistan
- Psychologist’s perspective
  Silvina Grana, Argentina

S-WE-01.3 – MULTIDISCIPLINARY

Family issues: From cradle to tween
Room: 252AB
Chair: Richa Mohan, India
- Effect and impact of bleeding disorder on the individual and the family
  Richa Mohan, India
- Maximizing the health of boys with hemophilia
  Dragan Micic, Serbia
- Family perspective and support
  Traci Marshall-Dowling, Ireland
- How to deal with diagnosis
  Asia Sayyadeh-Awajan, Jordan

S-WE-01.5 – DENTAL

Preventive and therapeutic management of oral and dental disease
Room: 251
Chair: Eduardo Rey, Argentina
- Periodontist issues
  Mariano Vassallo, Argentina
- Free paper: An investigation into the value and importance of oral health for people with hemophilia
  Alison Dougall, Ireland
• Free paper: Regular primary dental care access for patients with inherited bleeding disorders – the barriers and solutions
  Harpreet Kalsi, U.K.
• Free paper: Successful outcome following periodontal therapy for a patient with type 2B VWD and an atypical bleeding history
  Liam McEvanna, Ireland
• Free paper: Proper prophylaxis promotes good dental health in boys with hemophilia
  Hanna Rajantie, Finland

10:15-10:45
Refreshment break

PLENARY SESSIONS 10:45-12:15

PL-WE-02.1 – PLENARY 05
Room: Grand Amphitheatre
Chair: Claude Negrier, France
• Developing models of hemophilia care
  Alison Street, Australia

PL-WE-02.2 – PLENARY 06
Room: Grand Amphitheatre
Chair: Claude Negrier, France
• Prevention and prediction of inhibitor development
  Jan Astermark, Sweden

LUNCH BREAK & INDUSTRY SYMPOSIA
12:15-14:15

CONCURRENT SESSIONS 14:15-15:45

LB-WE-03.1 – MEDICAL
Late-breaking session II
Room: Grand Amphitheatre
Chair: Alison Street, Australia

S-WE-03.1 – MEDICAL
Models for Assessing Immunogenicity and Efficacy of New Therapeutics for the Treatment of Hemophilia
Room: Bordeaux Amphitheatre
Chair: Johannes Oldenburg, Germany
• Pre-clinical assessment of the immunogenicity of clotting factor products
  Birgit Reipert, Austria
• Assessing immunogenicity of clotting factor concentrates in humans
  Jean-Marie Saint-Remy, Belgium
• Models for assessing hemostatic efficacy of bypassing agents
  Dougald M. Monroe, U.S.A.

S-WE-03.2 – MULTIDISCIPLINARY
Ageing
Room: Salle Maillot
Chair: Jan Willem Andre de la Porte, South Africa
• Physical issues
  Megan Walsh, Australia
• Pain management in the older person with hemophilia
  Brenda Buzzard, U.K.
• The ageing MWH and sexuality
  Woet L. Gianotten, The Netherlands
• Ageing and oral health
  Alison Dougall, Ireland
• Impact of ageing from patient’s perspective
  Zygmunt Gruszka, Sweden

S-WE-03.3 – MULTIDISCIPLINARY
Patients: Members of the care team
Room: 252AB
Chair: David Silva Gomez, Spain
• Introduction and overview
  David Silva Gomez, Spain
• Advocating for oneself
  Daniel Andrei, Romania
• Enhanced communication skills
  Brian O’Mahony, Ireland
• Toolbox: Rules of thumb
  Carlos Safadi Márquez, Argentina

S-WE-03.5 – MUSCULOSKELETAL
Paediatric issues: Differences between developed and developing countries in hemophilia care
Room: 352AB
Co-chairs: Piet De Kleijn, The Netherlands, and Thierry Odent, France
• Prophylaxis regimen in developing countries
  Alok Srivastava, India
• Prophylaxis regimen in developed countries
  Erik Berntorp, Sweden
• Rehab in young PWH: Developing vs. developed countries
  Alina Ilesciu, Romania, and Pam Hillard, Canada
• Surgery in young PWH: Developing vs. developed countries
  Shubhranshu S. Mohanty, India, and Gianluigi Pasta, Italy
Closing the GAP: Continuum of development
Room: 251
Chair: Bruce Evatt, U.S.A.
- Introduction to the WFH Development Model 
  Bruce Evatt, U.S.A.
- Experience from a post-GAP country: How the WFH Development Model was used in Jordan 
  Arafat Awajan, Jordan
- Experience from a GAP country: How the WFH Development Model is being used in Thailand 
  Ampaiwan Chuansumrit, Thailand
- Experience from a GAP country: How the WFH Development Model is being used in Thailand 
  Monthon Suwannuraks, Thailand
- How the WFH Development Model can be used in the new WFH “Cornerstone Initiative” 
  Maria Satti, Sudan

15:45-16:30
Refreshment break and poster viewing

CONCURRENT SESSIONS 16:30-18:00

S-WE-04.1 – MEDICAL
How I treat inhibitors
Room: Grand Amphitheatre
Chair: Michael Makris, U.K.
- Immune tolerance induction 
  Charles Hay, U.K.
- Treatment and prevention of acute bleeds 
  Alessandro Gringeri, Italy
- Surgery 
  Roseline d’Orion, France

S-WE-04.4 – LABORATORY SCIENCES
Standards and monitoring treatment
Room: Bordeaux Amphitheatre
- Development of standards as a tool in bleeding disorder investigations during the 50-year development of the WFH 
  Trevor Barrowcliffe, U.K.
- Potency labelling of clotting factors 
  Anthony Hubbard, U.K.
- Practical aspects of monitoring post infusion levels 
  Steve Kitchen, U.K.

S-WE-04.2 – MULTIDISCIPLINARY
HTC comprehensive care – case studies
Room: Salle Maillot
- Hematologist from an established country 
  Georges Rivard, Canada
- Hematologist from an emerging country 
  Margareth Ozelo, Brazil
- Nurse 
  Mahmoud Ibrahim Abu Riash, Saudi Arabia
- Psychologist 
  Anthony Roberts, South Africa
- Physiotherapist – emerging country case study 
  Adly Sabbour, Egypt

S-WE-04.3 – MULTIDISCIPLINARY
Questions and answers: Sexual health
Room: 252AB
Chair: Lily Heijnen, The Netherlands
- PWH and Sexuality: A hemophilia nurse’s view 
  Anne-Louise Cruickshank, South Africa
- PWH and sexuality: A Sexual health professional’s view 
  Woet L. Gianotten, The Netherlands
- Physiotherapist’s perspective of sexual health in hemophilia 
  Greig Blamey, Canada
- Hematologist’s perspective of sexual health in hemophilia 
  Eveline Mauser-Bunschoten, The Netherlands

S-WE-04.5 – NURSE
Nursing beyond the treatment centre
Room: 352AB
Chair: James Munn, U.S.A.
- History/need and benefits of hemophilia camps 
  James Munn, U.S.A.
- Self infusion 
  Eliane Sandoval, Brazil
- Education 
  Jessica Li, China
- Impact of the hemophilia nurse on a camper 
  Paul Wilton, Canada
- Free paper: Cost-effectiveness of telephone counselling for Thai hemophilia receiving home treatment 
  Pakawan Wongwerawattanakoon, Thailand

S-WE-04.6 – PSYCHOSOCIAL
Parents empowering parents: A global perspective
Room: 251
Chair: Ed Kuebler, U.S.A.
- Facilitated by: 
  Ed Kuebler, U.S.A., and Danna Merritt, U.S.A.
Free papers 7: Inhibitors 2
Room: 241
Chair: Keith Hoots, U.S.A.

- Novel MHC-peptide- T cell receptor interfaces are necessary for inhibitor formation in mild/moderate haemophilia A secondary to missense mutation genotypes
  Dan Hart, U.K. (TBC)
- Predictors of success of immune tolerance induction in haemophilia A patients with high-responding inhibitors: A score from the Italian registry
  Antonio Coppola, Italy
- Assessment of treatment-related risk factors for inhibitor development in previously untreated hemophilia A patients: different statistical approaches
  Alfonso Iorio, Canada
- Hemophilia B mouse strains doubly humanized for human F9 and MHC Class II genes for study of inhibitors
  Paul E. Monahan, U.S.A.
- Evaluation of antibody responses to rFVIIIfc compared to Xyntha® and Advate® In hemophilia A mice
  Tongyao Liu, U.S.A.
- A factor Xa variant restores hemostasis in a hemophilia A dog model
  Debra Pittman, U.S.A.

INDUSTRY SYMPOSIA 18:15-19:45
**CONCURRENT SESSIONS 08:45-10:15**

**S-TH-01.1 – MEDICAL**

Clinical trial design in hemophilia
Room: Grand Amphitheatre
Chair: Donna DiMichele, U.S.A.
- Optimizing clinical trial design for product development in hemophilia
  Donna DiMichele, U.S.A.
- Definitions in hemophilia
  Victor Blanchette, Canada
- Observational studies and Health Technology Assessment (HTA)
  Erik Berntorp, Sweden

**FP-TH-01.1 – MEDICAL**

Free papers B: Gene expression and clotting factors
Room: 352AB
Chair: David Lillicrap, Canada
- Gene expression of coagulation factors in hepatocytes under structurally and functionally mimicked three dimensional hepatic tissues in vitro
  Kohei Tatsumi, Japan
- Measurement of ADAMTS13 in a factor VIII concentrate, 8Y®
  Sarah Kingsland, U.K.
- Normalization of blood coagulation with BAY 86-6150
  Annelie Siegemund, Germany
- Long-term follow up of liver-directed, Adeno-Associated Vector-mediated gene therapy in the canine model of hemophilia A
  David Lillicrap, Canada
- In mouse propagation of hemophilic hepatocytes toward gene correction and cell therapy
  Kazuo Ohashi, Japan
- Human FIX-P selectin chimeric protein expression in megacaryocytes derived from human hematopoietic cells
  Nathalie Enjolras, France

**S-TH-01.2 – MULTIDISCIPLINARY**

Family issues: Young adult
Room: Salle Maillot
Chair: Masood Malik, Pakistan
- Effect and impact of bleeding disorders on the individual and the family
  Shahla Sohail, Pakistan
- Coping strategies for young adults with severe bleeding disorders in Iran
  Ali Tabatabaey, Iran
- Psychological issues in sexuality
  Ed Kuebler, U.S.A.
- Step-by-step decisions: Career choices and employment challenges
  Paul Wilton, Canada

**S-TH-01.3 – MULTIDISCIPLINARY**

Developing educational models
Room: 252AB
Chair: Thomas Sannie, France
- Background and approach
  Jennifer Laliberte, Canada
- Models from NMOs
  Ludovic Robin, France
  Dan Farthing, U.K.
  Nadia Arkhipova, Russia
  Edwin Goh Toke Yen, Malaysia

**S-TH-01.4 – MUSCULOSKELETAL**

Management of the elbow joint
Room: 251
Co-chairs: Michael Heim, Israel, and Karen Beeton, U.K.
- Conservative management, splinting
  Greig Blamey, Canada
- Arthroscopic synovectomy of the elbow in hemophilia
  Carlos Rodriguez-Merchan, Spain
- Management of the established elbow flexion-contracture
  James Luck, U.S.A.
The symptomatic ulnar nerve: Is transposition the solution?
Horacio Caviglia, Argentina

Radial head resection
Adolfo Llinas, Colombia

Elbow arthroplasty
Nicholas Goddard, U.K.

10:15-10:45
Refreshment break

PLENARY SESSIONS 10:45-12:15

PL-TH-02.1 – PLENARY 07
Room: Grand Amphitheatre
Chair: Mark W. Skinner, U.S.A.
• Gene therapy for severe hemophilia B
  Ted Tuddenham, U.K.

PL-TH-02.2 – PLENARY 08
Room: Grand Amphitheatre
Chair: Mark W. Skinner, U.S.A.
• Inherited bleeding disease research: Opportunities for the World Federation of Hemophilia
  David Lillicrap, Canada

WFH AWARDS CEREMONY 12:30-14:00
Room: Salle Maillot
(Insert blurb)

CONCURRENT SESSIONS 14:15-15:45

S-TH-03.1 – MEDICAL
Debate of long-acting products versus gene therapy
Room: Grand Amphitheatre
Chair: Nigel Key, U.K.
• In favour of long acting products
  Paul Giangrande, U.K.
• In favour of gene therapy
  Katherine High, U.S.A.
• Patient perspective
  George McCoy, U.S.A.
  Ian Watkinson, U.K.

S-TH-03.4 – DENTAL
Surgical management of oral and dental problems
Room: 352AB
Chair: Andrew Brewer, U.K.
• Trauma
  Eduardo Rey, Argentina

FREE PAPERS

Free paper: Assessment of minimal clotting factor concentrate requirement for teeth extractions in patients with hemophilia
Natalie Stieltjes, France

Free paper: The Dental Wand – Is it cost-effective for patients with bleeding disorders?
Wendy Osborne, U.K.

Free paper: Last development in dental surgery in patients with hemophilia and inhibitors
Miryam Parreira, Argentina

Free paper: Dental implants in severe hemophilia case report
Vafa Jazayeri, Iran

S-TH-03.3 – MUSCULOSKELETAL
Arthropathy of the knee: When things go wrong
Room: Bordeaux Amphitheatre
Co-chairs: Pier Luigi Solimeno, Italy, and Adly Sabbour, Egypt
• Hemophilic knee arthropathy in developing countries
  Tariq Sohail, Pakistan
• Stiff knees: Physiotherapy in developing countries
  Pamela Narayan, India
• Stiff knee: Developed countries
• Total knee arthroplasty – infection
  Haroon A. Mann, U.K.
• Infection in TKA: Treatment outcomes
  Samir Mehta, U.S.A.
• The importance of the patients’ body awareness, auto-evaluation, empowerment, and allowing self help when things go wrong
  Christian Fondanesche, France

S-TH-03.2 – MULTIDISCIPLINARY
Working together: Lessons learnt
Room: 252AB
Chair: Alain Weill, France
• Model from Italy
  Gabriele Calizzani, Italy
• Lessons learnt from Dominican Republic
  Haydee Benoit De Garcia, Dominican Republic
• Lessons learnt from Poland
  Radoslaw Kaczmarek, Poland
• Model from the European Union: EURORDIS – The European Organisation for Rare Diseases
  Yann Le Cam, France
• Model from the European Union: DG Sanco
  Antoni Montserrat Moliner, Luxembourg

S-TH-03.5 – NURSE
Inhibitors: A nurse’s challenge
Room: Salle Maillot
Chair: Elizabeth Paradis, Canada

- Enhancing the nurse’s role for subjects with inhibitors
  Claude Meilleur, Canada

- Case studies: Pediatric
  Mbele Bongi, South Africa

- Case studies: Adolescent
  Robyn Shoemark, Australia

- Case studies: Adult
  Liljiana Rakic, Serbia

- Case studies: Mild hemophilia – older patient
  Johan Vandesande, Belgium

S-TH-03.6 – PSYCHOSOCIAL

Coping strategies
Room: 251
Chair: Silvina Grana, Argentina

- Coping with transitions in adulthood
  Susan Cutter, U.S.A.

- Strategies and tools for coping with hemophilia for children and families
  Silvina Grana, Argentina

- Coping responses to hemophilia
  Richa Mohan, India

- Topic TBD
  Sylvia von Mackensen, Germany

- Implementation of an educational and psychosocial support program
  Lara Oyesiku, U.K.

FAREWELL DINNER 19:00-24:00