Professional development workshops

SUNDAY, July 8, 2012

- Nurse’s workshop (08:30-15:00)
- Psychosocial workshop (09:15-16:15)
- Orthopedics workshop (14:30-16:00)
- Laboratory sciences workshop (09:00-12:00)
- Women & Bleeding Disorders workshop (13:00-16:00)
- Clinical research workshop (08:30-12:30)
- Publishing workshop–Wiley-Blackwell (13:30-15:00)
- Gene therapy workshop (15:30-17:00)

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Nurse’s workshop
08:30-15:00 (sponsored by Baxter)
ROOM: 241
Chair: Elizabeth Paradis, Canada

08:30 Introduction
Elizabeth Paradis, Canada

08:45 Where in the world
WFH Nurses Committee

09:00 Nurses Manual: A new resource
Penny McCarthy, Australia

09:45 BREAK

10:00 A practical guide to the joint examination
Anne Powell, Australia

10:45 Hot topic: Fidél’hem in action
Patricia Guillon, France

11:15 Evaluation of burnout and job satisfaction
Karen Wulff, U.S.A.

12:05 LUNCH

13:00 Introducing nursing research:
Improving hemophilia care by engaging nurses in clinical research
Kate Khair, U.K.

13:30 Developing an abstract/poster
Martin Bedford, U.K.

14:00 Nursing research
Free paper: Are nurse education programs effective? Evaluation of a program offered in South Africa
Jill Smith, Australia

The prevalence of stomatology
Jessica Li, China

Studies in hemophilia: A short review
Karin Lindvall, Sweden

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

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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.
Professional development workshops

SUNDAY, July 8, 2012

PRE CONGRESS SESSIONS

Research in sports assessment
Sylvia von Mackensen, Germany
12:00 LUNCH & SYMPOSIUM
Chair: Ruud Bos, The Netherlands
12:30 HERO results
Frederica Cassis, Brazil and Alfonso Iorio, Canada
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 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 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

Lab science: Pre-analytical variables and coagulometer evaluation
09:00-12:00 (Sponsored by Grifols)
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  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.  
Sukshe Nair, India

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  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

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**Women & bleeding disorders workshop**

**13:00-16:00**

**ROOM: 252AB**

Chair: Rezan Kadir, U.K.

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13:00  Multidisciplinary clinic for women with bleeding disorders  
Rochelle Winikoff, Canada
Clinical research workshop
08:30-12:30
ROOM: 352AB
Co-chairs: Frits Rosendaal, The Netherlands and David Lillicrap, Canada

Clinical studies: The right design for the right question
Frits Rosendaal, The Netherlands

Observational studies on inhibitor development:
What have they taught us
Anske van der Bom, The Netherlands

Bleeding scores: How do we make, test, and use them
Alberto Tosetto, Italy

New drugs, new problems
Flora Peyvandi, 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 Vandendriesche, Belgium

Organization of gene therapy clinical trials
Margareth Ozelo, Brazil
The prevalence of hypertension in hemophilia – a single centre experience
Wassel C, Kolaitis Wassel N, Elias D, Waalen J, von Drygalski A

Tosetto Bleeding Score and factor VIII or IX levels in hemophilia carriers

Low factor VIII is associated with bleeding during early pregnancy
James A, Miller C, Byams V, Thames B, Philipp C

The prevalence of disorders of hemostasis in adolescent girls with menorrhagia
Linari S, Bruni V, Paladino E, Serravalli V, Montorzi G, Pampaloni F, Morfini M

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

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-01.4 – 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
Naderi M., Eslighi P., Cohan N., Karimi M.

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

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

La Butte Montmartre, Le Sacré-Coeur
The potential role of synovial thrombomodulin in the pathophysiology of joint bleeds in hemophilia

Pseudotumor surgery in hemophilia A patients: Comparative results between inhibitor and non-inhibitor patients
Caviglia H, Candela M, Douglas Price A, Alejandra B, Neme D, Perez Bianco R

Arthroscopic ankle arthrodesis for hemophilic arthropathy

Compartment syndrome in patients with inhibitors
Donaldson J, Goddard N

186Re radiosynovectomy for chronic synovitis in children with hemophilia
Laguna P, Cwikla J, Zbikowski P, Klukowska A, Matysiak M

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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

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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

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FP-MO-03.3 – MUSCULOSKELETAL
Free papers I
ROOM: 352AB
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
Fischer K, de Kleijn P
factor IX with albumin (rIX-FP) in patients with hemophilia B (PROLONG-9FP)
Santagostino E

Example from Egypt
Nadia Moharram, Egypt

Example from Belarus
Siarhei Misevich, Belarus

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
Deon 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

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

16:30-18:00 CONCURRENT SESSIONS

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 – 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
Kalnins W, Querol F, Gregory M, Iorio A

Age at the first bleeding could be a predictor of hemorrhagic phenotype in patients with severe hemophilia

Adherence to prophylaxis in The Netherlands: A multicentre study
Schrijvers L, Beijlevelt-van der Zande M, Peters M, Lock J, Cnossen M, Schuurmans M, Fischer K

Prophylaxis Versus On-demand Therapy Through Economic Report (P.O.T.T.E.R.) study: Preliminary data from the final 5 years analysis

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
Soucie M

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
Balliel W, Zillekens J

**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
Congress sessions
TUESDAY, July 10, 2012

07:00-08:30 INDUSTRY SYMPOSIA
08:45-10:15 CONCURRENT SESSIONS

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 II: 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
Von Drygalski A, Cramer T, Griffin J, Gale A, Mosnier L
Efficacy of prophylactic treatment with Human-cl rhFVIII in previously treated patients with severe haemophilia A
One year clinical experience with solvent/detergent-filtered (SD-F) cryoprecipitate
El-Ekiaby M, Goubran H, Radošević M, El Ekiaby A, Burnouf T

Enhanced phosphorylation and sulfation of human recombinant factor IX for production by the hepatoma cell line HuH-7
Enjolras N, Dargaud Y, Perot E, Guillaume F, Becchi M, Negrier C

Patients with hemophilia A and B have increased platelet TFPI
Ellery P, Maroney S, Hilden I, Sorensen B, Gill J, Mast A
GlycoPEGylated rFVIII (N8-GP) has prolonged hemostatic effect in hemophilia A mice
Elm T, Johansen P, Ovilsen K, Möller F, Holmberg H, Tranholm M, Ezban M, Stennicke H

FP-TU-01.2 – MUSCULOSKELETAL
Free papers II
ROOM: 352AB
Physical activity measured by high-frequency accelerometry in boys with hemophilia
Risk of bleeds associated with physical activity in children with hemophilia
Endurance performance in adult hemophilia patients before and after a three-month sports therapy program: a randomized controlled trial (RCT)
Joint distraction results in clinical and structural improvement of hemophilia ankle arthropathy: A
Free paper: Experience of circumcision using low quantities of factor concentrates
Seck M, Gueye M, Sagna A, Faye B, Sy Bah D, Leye M, Sall Fall A, Toure Fall A, Fall I, Diop S
Developing minimal factor use scenarios
Indu Mariya, India
Case histories: Adult
Georgina Floros, Canada
Case studies: Pediatrics
Ana Claudia Acerbi Vrabic

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: Dorothee Pradines, France
Feet 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 Huaynay, Peru
Youth programs and concepts from an established country
Dorothee 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
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
Nidagala Keshava Shyamkumar, India
Quality of life assessment
Brian Feldman, Canada

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 Witkap, 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

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

16:30-18:00 CONCURRENT SESSIONS

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
A new class of mutations in the A3 region of von Willebrand factor inducing multiple functional defects in the protein
Christophe O. Legrande P, Navarrete A, Rayes J, Boisseau, Ternisien, Caron, Fressinaud E, Goudemand J, Veyradier A, Lenting P, Denis C
Pharmacokinetics, safety, and efficacy of a high purity factor X in patients with severe and moderate hereditary factor X deficiency
**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 Favalaro, Australia

**Diagnosis of FXIII deficiency**

Hans-P Kohler, Switzerland

**WFH External Quality Assessment (EQA) program**

Ian Jennings, U.K.

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**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 Salou Diop, Senegal

Research and ethical aspects of clinical trials

Johnny Mahlangu, South Africa

General outreach: The Kenya experience

Fatimah Abdallah, Kenya

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**VWD outreach**

Magdy El Ekiaby, Egypt

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**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

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**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

Bluth B, Fong Y, Houman J, Luck J, Silva M

Association of hemophilic arthropathy with genetic markers related to bleeding tendency, joint inflammation, and structural cartilage

Lopez-Jimenez J, Soto-Padilla J

A population-based longitudinal study of musculoskeletal disorders in people with hemophilia, and their matched controls


IL-6 receptor antagonist as adjunctive therapy for the prevention and treatment of bleeding-induced arthropathy

Narkbunnam N, Sun J, Hu G, Mihara M, Monahan P

Plasmin-induced proteoglycan release in human cartilage is PAR-dependent

Nieuwenhuizen L, Schutgens R, Roosendaal G, Biesma D, L afeber F

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


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**18:00-20:00 CULTURAL EVENT**
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

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
Dougall A, Lador J

Free paper: Regular primary dental care access for patients with inherited bleeding disorders – the barriers and solutions
Kalsi H, Nanayakkara L, Danga E, Bowles L, Jones J, Pasi J, Hart D

Free paper: Successful outcome following periodontal therapy for a patient with type 2B VWD and an atypical bleeding history
McElvanna L, O’Connell N

Free paper: Proper prophylaxis promotes good dental health in boys with hemophilia
Rajantie H, Alapulli H, Ranta S, Makipernaa A

10:15-10:45 REFRESHMENT BREAK
10:45-12:15 PLENARY SESSIONS

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

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

14:15-15:45 CONCURRENT SESSIONS

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 Marquez, 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 Ilescu, Romania, and Pam Hillard, Canada

Surgery in young PWH: Developing vs. developed countries
Shubhranshu S. Mohanty, India, and Gianluigi Pasta, Italy
S-WE-03.4 – WFH
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 Suwannaraks, Thailand

How the WFH Development Model can be used in the new WFH “Cornerstone Initiative”
Maria Satti, Sudan

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

16:30-18:00 CONCURRENT SESSIONS

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
Co-chairs: Trevor Barrowcliffe, U.K., and Anthony Hubbard, U.K.

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
Chair: Brian O’Mahony, Ireland

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 sexual health: 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.
Evaluation of antibody responses to rFVIIIFc compared to Xyntha® and Advate® In hemophilia A mice
Liu T, Hoehn T, Patarroyo-White S, Pierce G, Jiang H

A factor Xa variant restores hemostasis in a hemophilia A dog model

18:15-19:45 INDUSTRY SYMPOSIA

Self infusion
Eliane Sandoval, Brazil

Change lives through widespread education on hemophilia
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

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.

FP-WE-04.2 – MEDICAL
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
Skelton S, Moss D, Sansom C, Gomez K, Shepherd A, Hart D

Predictors of success of immune tolerance induction in haemophilia A patients with high-responding inhibitors: A score from the Italian registry

Assessment of treatment-related risk factors for inhibitor development in previously untreated hemophilia A patients: different statistical approaches

Hemophilia B mouse strains doubly humanized for human F9 and MHC Class II genes for study of inhibitors
Congress sessions

THURSDAY, July 12, 2012

08:45-10:15 CONCURRENT SESSIONS

S-TH-01.1 – MEDICAL

Trial updates and standardization issues
ROOM: GRAND AMPHITHEATRE
Chair: Alison Street, Australia

- Results from the Rodin study
  Marijke Vandenbargh, The Netherlands

- Exposure date data
  Nisha Jain, U.S.A.

- MUSFIH study
  Alok Srivastava, India

- Potency labels of clotting concentrates
  Tony Hubbard, U.K.

FP-TH-01.1 – MEDICAL

Free papers 8: 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
  Tatsumi K, Ohashi K, Kim K, Utoh R, Okano T

- Measurement of ADAMTS13 in a factor VIII concentrate, 8Y*
  Bolsa H, Kingsland S, Feldman P

- Normalization of blood coagulation with BAY 86-6150
  Siegemund A, Adam N, Scholz U, Schobess R, Siegemund T

- Long-term follow up of liver-directed, Adeno-Associated Vector-mediated gene therapy in the canine model of hemophilia A
  Lillicrap D, Harpell L, Labelle A, Webster S

- In-mouse propagation of hemophilic hepatocytes toward gene correction and cell therapy

- Human FIX-P selectin chimeric protein expression in megacaryocytes derived from human hematopoietic cells
  Chevalier Y, Dargaud Y, Enjolras N, Negrier C

S-TH-01.5 – LABORATORY SCIENCES

Genetics of hemostasis
ROOM: BORDEAUX AMPHITHEATRE

- Development of genetics as a tool in bleeding disorder investigations during the 50-year development of the WFH
  Ted Tuddenham, U.K.

- Genetic analysis in bleeding disorders: What is the state of the art?
  Anne Goodeve, U.K.

- The UK NEQAS Haemophilia Molecular Genetics Quality Assurance Scheme
  David Perry, U.K.

- Reference materials for genetic tests in hemophilia and allied bleeding disorders
  Elaine Gray, U.K.
**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 Tabatabaee, 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.
  - Nadiya 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**

**10:45-12:15 PLENARY SESSIONS**

**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

- The World Federation of Hemophilia and research
  - David Lillicrap, Canada

**12:30-14:00 WFH AWARDS CEREMONY**
ROOM: SALLE MAILLOT

Join us for the 2012 edition of the WFH Awards Ceremony where we will honour and celebrate our most devoted volunteers.

**14:15-15:45 CONCURRENT SESSIONS**

**S-TH-03.1 – MEDICAL**
Debate of long-acting products versus gene therapy
ROOM: GRAND AMPHITHEATRE
Chair: Nigel Key, U.S.A.

- In favour of long acting products
  - Paul Giangrande, U.K.
- In favour of gene therapy
  - Katherine High, U.S.A.
- Patient perspectives
  - 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 paper: Assessment of minimal clotting factor concentrate requirement for teeth extractions in patients with hemophilia
Stieljes N, Roussel-Robert V, Alantar A, Ounnoughene N, Albinni S, Hassin M

Free paper: The Dental Wand – Is it cost-effective for patients with bleeding disorders?
Osborne W, Woyles J, Walton G, Talks K

Free paper: Last development in dental surgery in patients with hemophilia and inhibitors
Parreira M, Rey E, Candela M, Neme D, Perez Bianco R, Tezanos Pinto M

Free paper: Dental implants in severe hemophilia case report
Jazayeri V

S-TH-03.3 – MUSCULOSKELETAL
Arthropathy of the knee: When things go wrong
ROOM: BORDEAUX AMPHITHEATRE
Co-chairs: Luigi Piero 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 Fondaenesche, 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
Hayde 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 Moller, 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