Programme for the pre-congress day for Nurses and Physiotherapists

TUESDAY 31st January
9.30-18.00

9.30-10.15: Welcome
10.15-12.30: Pre-meeting multidisciplinary session (Nurses and Physiotherapists Committees)

Chair: Sébastien Lobet
1) Introduction (Roseline d’Oiron and Cédric Hermans)
2) The contribution of nursing to effective haemophilia care (Francoise Bonfils, Elsbeth Müller-Kägi)
3) The contribution of physiotherapists to effective haemophilia care (David Stephensen, Sébastien Lobet, Piet de Kleijn, Marie Katzerová)
4) The necessity of a psychological care as part of a multidisciplinary approach (Perrine Limperg, Lotte Haverman)
5) Combined work between hematologist, nurse and physiotherapist: a vision for haemophilia care for the next 10 years (Cédric Hermans)

12.30-13.30: Lunch

13.30-17.00: Parallel sessions: Nurses Committee
Evidenced-based haemophilia nursing care: are we doing it right?

Chair: Martin Bedford
1) FIDELHEM: presentation from the group of nurses in Haemophilia Treatment Centres in France (Malika Makhloufi)
2) Introducing the EAHAD nursing guidelines: Process and rationale (Martin Bedford)
3) Guidelines for intravenous and central venous access device (CVAD) infusion in bleeding disorders
   - Infusion video (Elisbeth Müller-Kägi)
   - Gloves or no gloves? (Kate Khair)
   - Mothers perspectives on treatment (Charlotte von der Lippe)

15:00-15:15 Break

4) Self-management
   - Facilitation of self management (Martin Bedford)
   - Case study: Needle phobia (Siri Grønhaug)
   - Two novel programs to improve self-management in haemophilia: the first outcomes (Marlies Schrijvers)
5) Surgery
- Comprehensive Care Pathway for surgical management of patients with bleeding disorders (Alpha-Umar Barrie)
- Haemophilia and surgery: do no further harm (Nanda Uitslager)
- Case study: knee surgery (Ljiljana Rakic)
- Discussion

6) Concluding comments

13:30-17.00: Parallel sessions: Physiotherapists Committee
13:30-15:00 Session I: The haemophilic ankle, the acute phase

Chair: Ann McCarthy
1) Pathophysiology of haemophilic ankle arthropathy (Sébastien Lobet)
2) The haemophilic ankle in children: use of the Haemophilia Joint Health Score (HJHS) (Hannah Harbridge, Nathalie Grinda)
3) The assessment of the hindfoot, midfoot and forefoot with other clinical tests than Haemophilia Joint Health Score (HJHS) (Benjamin Hidalgo, Sofia Perez)
4) Treatment in subacute phase to return to pre-existing function and more (Hannah Harbridge, Nathalie Grinda)

15:00-15:15 Break

15:15-17.00 Session II: The haemophilic ankle, the chronic phase

Chair: Gaétan Duport
1) Orthopedic manual therapy (OMT) for the haemophilic ankle arthropathy: value and perspectives (Ruben Custa-Barriuso)
2) OMT in the treatment of the end-stage haemophilic ankle arthropathy in practice (Benjamin Hidalgo, Ruben Cuesta-Barriuso)
3) The role of ankle ortheses in haemophilic arthropathy (Kevin Deschamps)
4) The role of physiotherapist in Summer Camp (Marie Katzerova)
5) Concluding comments

17:00-18:00: Networking
Programme for EAHAD Paris 2017

WEDNESDAY 1st February
9.30-20.30

9.30-11.00: Multidisciplinary educational session

Chair: Riitta Lassila and Philippe de Moerloose
Patients with severe bleeding disorders: A multidisciplinary approach towards the partnership between patients and the caregiver team. (Joana Baquero, Philippe de Moerloose, Petra Elfvinge, Riitta Lassila, Paul McLaughlin, Thomas Sanné)

11.00-11.30: Coffee break & Poster viewing

11.30-13.00: Industrial symposia (LFB Biomédicaments – Shire)
13.00-14.00: Break

14.00-15.30: Industrial symposia (Medscape – Pfizer)
15.30-16.00: Coffee break & Poster viewing

16.00-17.30: Industrial symposia (Octapharma – Biotest)
17.30-18.00: Coffee break & Poster viewing

19.30-20.30: Welcome reception

THURSDAY 2nd February
7.45-19.15

7.45-9.15: Morning cases I & II

Chair: Karin Fijnvandraat and Victor Jimenez-Yuste
1) How to prepare and manage pregnancy in a carrier of haemophilia? (Clare Tower and Sue Pavord)
2) How to initiate treatment in a severe haemophilia A Previously Untreated Patient (PUP)? (Maria Elisa Mancuso and Jan Astermark)

9.15-9.45: Coffee break & Poster viewing

9.45-10.00: Welcome and introduction
Roseline d'Oiron

10.00-11.00: Session 1: Successes and challenges of haemophilia care in 2017: a European perspective

Chair: Cédric Hermans and Philippe de Moerloose
1) The European Commission Expert Group on Rare Diseases and the Haemophilia Community (Amanda Bok)
2) European Reference Networks and EuroBloodNet (Mike Makris)

11.00-11.30: Break & Poster viewing  
Foyer Level 0/-1

11.30-13.00: Session 2: Immunology in haemophilia: from concepts to practice or vice versa  
Room ABCDEF  
*Chairs: Sébastien Lacroix-Desmazes and Roseline d'Oiron*  
1) After the danger theory, is the discontinuity theory the next paradigm to understand immune response? (Thomas Pradeu)  
2) Regulation of Inflammation By Intestinal Microbiota (Gerard Eberl)  
3) Vaccination and anti-factor VIII immune response: what brings real life data (Marijke van den Berg)

13.00-14.00: Lunch & Poster session I  
Foyer Level 0/-1

13.15-13.45: EAHAD Annual General meeting  
Room ABCDEF  
(for EAHAD Members only)

14.00-15.30: Session 3: Pain in haemophilia  
Room ABCDEF  
*Chairs: Gerry Dolan and Sébastien Lobet*  
1) Perception of other’s pain: between resistance and denial or why physicians undervalue patient’s pain (Nicolas Danziger)  
2) Thinking beyond muscles and joints: The importance of altered central pain mechanisms in patients with chronic pain (Nathalie Roussel)  
3) The Good, the Bad, and the Ugly of analgesics used for patients with haemophilia (Nicholas Moore)

15.30-16.00: Coffee break & Poster session II  
Foyer Level 0/-1

16.00-17.30: Session 4: Celebrate the 10th anniversary of EAHAD with Factor X  
Room ABCDEF  
*Chairs: Flora Peyvandi and Jean-François Schved*  
1) Factor X variants to help unmet needs in haemophilia (Olivier Christophe)  
2) Factor X constitutional deficiencies: diagnostic and therapeutic challenges (Flora Peyvandi)  
3) A new step forward to understand acquired Factor X deficiencies (Vincent Muczynski)

17.30-17.45: Coffee break & Poster viewing  
Foyer Level 0/-1

17.45-19.15: Session 5: SLAM session (10 abstracts selected for oral presentation)
Room ABCDEF

**Chairs: Robert Klamroth and Jan Blatny**

**OR15:** VON WILLEBRAND DISEASE TYPE 2M: CORRELATION BETWEEN GENOTYPE AND PHENOTYPE (Dominique Maas)

**OR16:** NO ASSOCIATION BETWEEN HFE AND HMOX1 POLYMORPHISMS, IMPORTANT IN IRON AND HEME HANDLING, AND THE SEVERITY OF HAEMOPHILIC ARTHROPATHY (Lize F.D. van Vulpen)

**OR17:** REAL WORLD PROSPECTIVE DATA ON BLEEDING FREQUENCY IN 1,000 PATIENTS WITH HEMOPHILIA A – IS THE GOAL OF ZERO BLEEDS ACHIEVABLE? (Alessandro Gringeri)

**OR18:** INTER-RATER RELIABILITY OF PHYSIOTHERAPISTS USING THE HEAD-US PROTOCOL TO EVALUATE EARLY JOINT DISEASE (David Stephensen)

**OR19:** BLEEDING FVIII INHIBITOR PATIENTS – DATA FROM THE REMAIN STUDY OF THE PEDNET STUDY GROUP (Kathelijn Fischer)

**OR20:** HAEMOPHILIC PSEUDOTUMORS OF THE LIMBS. 25 YEARS EXPERIENCE OF MINI INVASIVE SURGERY (Horacio Caviglia)

**OR21:** OBSERVATORY ON THE MANAGEMENT OF CARDIOVASCULAR DISEASE IN HEMOPHILIA PATIENTS – THE “COCHE” STUDY (Jean-François Schved)

**OR22:** STUDY OF PHYSICAL FUNCTION IN ADOLESCENTS WITH HAEMOPHILIA: THE SO-FIT STUDY (Kate Khair)

**OR23:** MANAGEMENT OF BLEED EVENTS IN THE PHASE 1 STUDY OF FITUSIRAN, AN INVESTIGATIONAL RNAI THERAPEUTIC TARGETING ANTITHROMBIN FOR THE TREATMENT OF HEMOPHILIA IN PATIENTS WITH AND WITHOUT INHIBITORS (Savita Rangarajan)

**OR24:** IN VITRO CHARACTERIZATION OF F376A/M388A-SOLULIN, A NEW PROMISING ANTIFIBRINOLYTIC FOR SEVERE HAEMOPHILIA A (Yohann Repesse)

19.15: Networking

**FRIDAY 3rd February**

**7.45-14.40**

**7.45-8.30:** Morning case III

*Room ABCDEF*

*Chairs: Gerry Dolan and Pål Andre Holme*

Cardiovascular indications of antiagregants or anticoagulants in haemophilia (Dan Hart and Ceri Davies)

**8.30-10.00:** Session 6: Do not forget Red Blood Cells

*Room ABCDEF*

*Chairs: Alessandro Casini and Riitta Lassila*

1) Contribution of red blood cells to clot structure: how does it apply to bleeding disorders? (Robert Ariens)

2) When something is wrong with iron: What clinicians of Haemophilia Centres should know about hepcidin metabolism? (Zoubida Karim)

3) New frontiers, challenges and evolving treatment paradigms for iron deficiency anemia in patients with bleeding disorders (Sigismond Lasocki)
10.00-10.30: Coffee break & Poster viewing  

10.30-12.00: Session 7: Future perspectives  
Chairs: Claude Négrier and Robert Klamroth  
1) How to make a choice between the different extended half-life products? (John Pasi)  
2) Gene therapy in haemophilia: where are we? (Thierry VandenDriessche)  
3) New non substitutive therapeutic options in haemophilia: how to pick up the right flower among the current flourishing bouquet? (Johannes Oldenburg)  

12.00-12.30: The Arosenius Lecture 2017  
Chairs: Jan Astermark and Sophie Susen  
Importance of phenotypic and genotypic characterization for treatment of Von Willebrand Disease: lessons from the French cohort (Jenny Goudemand)  

12.30-13.00: Session 8: Hot topics  
Chairs: Mike Makris and Cédric Hermans  
1) OR33: INHIBITOR DEVELOPMENT IN PREVIOUSLY UNTREATED PATIENTS WITH SEVERE HAEMOPHILIA A TREATED WITH HUMAN-CL RHFVIII, A NEW GENERATION RECOMBINANT FVIII OF HUMAN ORIGIN (Ellis J Neufeld)  
2) OR35: PRELIMINARY INTERIM DATA FROM PHASE 1/2 TRIAL: SPK-9001-ADENO-ASSOCIATED VIRUS MEDIATED GENE TRANSFER FOR HAEMOPHILIA B - ACHIEVES SUSTAINED THERAPEUTIC FACTOR IX ACTIVITY LEVELS WITHOUT REPETITIVE INFUSIONS (Marcus E. Carr)  
3) OR36: SYNERGISTIC EFFECTS OF A PROCOAGULANT BISPECIFIC ANTIBODY AND FEIBA OR FACTOR VIIA ON THROMBIN GENERATION (Rudolf Hartmann)  
4) OR37: IN VITRO THROMBIN GENERATION TESTING AND IN VIVO VENOUS STASIS MODEL FOR ASSESSING THE PRO-COAGULANT EFFECTS OF FVIII, EMICIZUMAB, RFVIIA, AND APCC. (Joanne I. Adamkewicz)  

13.00-13.40: Poster and Research Grant Awards  
Chairs: Cédric Hermans and Victor Jimenez-Yuste  

13.40-13.50: Closing remarks  
(Roseline d’Oiron)  

13.50-15.00: Lunch