

# Programme for the pre-congress day for Nurses and Physiotherapists

TUESDAY 31<sup>st</sup> January  
9.30-18.00

9.30-10.15: [Welcome](#)

*Room Loft GH*

10.15-12.30: [Pre-meeting multidisciplinary session \(Nurses and Physiotherapists Committees\)](#)

*Room Loft GH*

*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](#)

*Outside Session Room*

13.30-17.00: [Parallel sessions: Nurses Committee](#)

[Evidenced-based haemophilia nursing care: are we doing it right?](#)

*Room Loft G*

*Chair: Martin Bedford*

- 1) FIDELHEM: presentation from the group of nurses in Haemophilia Treatment Centres in France (Malika Makhoulfi)
- 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 (Elsbeth Müller-Kägi)
  - Gloves or no gloves? (Kate Khair)
  - Mothers perspectives on treatment (Charlotte von der Lippe)

15:00-15:15 Break

*Outside Session Room*

- 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-Umaru 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](#)

*Room Loft H*

*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

*Outside Session Room*

15:15-17:00 [Session II: The haemophilic ankle, the chronic phase](#)

*Room Loft H*

*Chair: Gaétan Duport*

- 1) Orthopedic manual therapy (OMT) for the haemophilic ankle arthropathy: value and perspectives (Ruben Cuesta-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 orthoses in haemophilic arthropathy (Kevin Deschamps)
- 4) The role of physiotherapist in Summer Camp (Marie Katzerova)
- 5) Concluding comments

17:00-18:00: [Networking](#)

*Outside Session Room*

# Programme for EAHAD Paris 2017

## WEDNESDAY 1<sup>st</sup> February

9.30-20.30

9.30-11.00: **Multidisciplinary educational session**

**Room AB**

*Chairs: 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 Sannié)

11.00-11.30: Coffee break & Poster viewing

**Foyer Level 0/-1**

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

**Room AB / Room CDEF**

13.00-14.00: Break

**Foyer Level 0/-1**

14.00-15.30: Industrial symposia (*Medscape – Pfizer*)

**Room AB / Room CDEF**

15.30-16.00: Coffee break & Poster viewing

**Foyer Level 0/-1**

16.00-17.30: Industrial symposia (*Octapharma – Biotest*)

**Room AB / Room CDEF**

17.30-18.00: Break & Poster viewing

**Foyer Level 0/-1**

18.00-19.30: Industrial symposia (Novo Nordisk – Sobi)

**Room AB / Room CDEF**

19.30-20.30: Welcome reception

**Foyer Level 0/-1**

## THURSDAY 2<sup>nd</sup> February

7.45-19.15

7.45-9.15: **Morning cases I & II**

**Room ABCDEF**

*Chairs: 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

**Foyer Level 0/-1**

9.45-10.00: **Welcome and introduction**

**Room ABCDEF**

Roseline d'Oiron

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

**Room ABCDEF**

*Chairs: 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](#)  
(for EAHAD Members only) *Room ABCDEF*

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 10<sup>th</sup> 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 3<sup>rd</sup> 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 *Foyer Level 0/-1*
- 10:30-12.00: **Session 7: Future perspectives** *Room ABCDEF*  
*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** *Room ABCDEF*  
*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)
- 12.30-13.30: **Session 8: Hot topics** *Room ABCDEF*  
*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)
- 13.30-13.40: **Poster and Research Grant Awards** *Room ABCDEF*  
*Chairs: Cédric Hermans and Victor Jimenez-Yuste*
- 13.40-13.50: **Closing remarks** *Room ABCDEF*  
(Roseline d'Oiron)
- 13.50-15.00: Lunch *Foyer Level 0/-1*