

### **Conference Programme**

Friday, 6 October 2023

08.30-09.30 - Haemophilia in Croatia

09.35-10.35 - Multidisciplinary Care

11.05-12.05 - von Willebrand Disease

12.35-13.20 - Novo Nordisk Symposium

13.25-14.10 - Sobi Symposium

14.40-15.40 - ERIN

15.45-16.45 - Women and Bleeding Disorders

17.15-19.30 - EHC General Assembly

(EHC Members and Patient reps. only)

Saturday, 7 October 2023

08.00-08.45 - WFH Members Meeting

(WFH Members only)

09.00-10.00 - Novel Therapies

**10.05-11.05 - Pain Management** 

11.35-12.35 -Gene Therapy

13.05-13.50 - Roche Symposium

13.55-14.40 - Sanofi Symposium

15.10-16.10 - Mental Health and Youth Debates

16.15-17.30 - SLAMS

17.45-19.00 - Nordic Walking Workshop and City Tour

Sunday, 8 October 2023

08.00-08.50 - PROBE Workshop

09.00-10.15 - Ageing and Bleeding Disorders

10.20-11.05 - BioMarin Symposium

11.35-12.20 - CSL Behring Symposium

12.25-12.55 - Conference closing and take-aways



# Conference Programme Friday, 6 October 2023

#### Haemophilia in Croatia

08.30-09.30 hrs

#### **Chaired by Olivia Romero Lux and Marko Marinić**

- Opening and welcome to the Conference
- Haemophilia Care in Croatia
  - o Ana Boban
- Quality of life of people with haemophilia in Croatia
  - o Marko Marinić
- Video on the work of the Croatian Haemophilia Association
- Q&A and session closure

#### **Multidisciplinary care**

09.35-10.35 hrs

#### Chaired by Stefan Radovanović and Fariba Baghaei

- Opening to the session and speakers introduction
- Comprehensive Care for paediatric patients in the next five years
  - Beatrice Nolan
- Comprehensive care for adult patients in the next five years
  - o Pratima Chowdary
- Shared decision-making and advocating for care
  - o Sara Garcia Barcenilla
- Q&A and session closure

#### von Willebrand Disease

11.05-12.05 hrs

#### Chaired by Manon Degenaar-Dujardin and Ernest Bilić

- Opening to the session and speakers introduction
- Life pathways
  - Matt Johnson
- Redefining needs
  - Sunny Maini and Jo Traunter
- Potential future therapies
  - Michelle Lavin
- Q&A and session closure



## **Conference Programme** Friday, 6 October 2023

#### **European Rare and Inhibitor Network (ERIN)**

14.40-15.40 hrs

#### **Chaired by Evelyn Grimberg and Karin Fijnvandraat**

- Opening to the session and speakers introduction
- Current and future needs of patients with inhibitors
  - Victor Jimenez Yuste
- ERIN Inclusion of all bleeding disorders
  - Miguel Crato
- Basket trials changes that we need
  - Marc Dooms
- Q&A and session closure

#### **Women and Bleeding Disorders**

15.45-16.45 hrs

#### **Chaired by Diana Lighezan and Naja Skouw-Rasmussen**

- Opening to the session and speakers introduction
- Improving diagnosis and care pathways
  - Michelle Lavin
- Engaging women Ambassadors update
  - Yannick Collé
- Putting yourself first
  - Karola Diosí
- Q&A and session closure



### Conference Programme Saturday, 7 October 2023

#### **Novel Therapies**

09.00-10.00 hrs

#### **Chaired by Mariëtte Driessens and Mike Makris**

- Opening to the session and speakers introduction
- Next generation extended half-life replacement therapies
  - Speaker TBC
- Current state of rebalancing agents
  - Cedric Hermans
- Bi-specific antibodies: Old, new, repurposed
  - o Victor Jimenez Yuste
- Q&A and session closure

#### **Pain Management**

10.05-11.05 hrs

#### Chaired by Marko Marinić and Piet De Kleijn

- Opening to the session and speakers introduction
- Micro-bleeds and the importance of joint health
  - o Paul McLaughlin
- Pain and physiotherapy across Europe
  - David Stephenson
- Patient perspective
  - Dejan Petrović
- Q&A and session closure

#### **Gene Therapy**

11.35-12.35 hrs

#### **Chaired by Brian O'Mahony and Wolfgang Miesbach**

- Opening to the session and speakers introduction
- Gene therapy, a personal perspective
  - o Shagi Galili
- Gene therapy the German experience
  - Wolfgang Miesbach
- Panel discussions on 'Are we ready? Making decisions on treatment products in a world of replacement, non-replacement and gene therapy.
  - Brian O'Mahony (moderator), Shagi Galili, Wolfgang Miesbach and Glenn Pierce
- Q&A and session closure



### Conference Programme Saturday, 7 October 2023

#### **Mental Health and Youth Debates**

15.10-16.10 hrs

#### **Chaired by Manon Degenaar-Dujardin and Kruno Sokol**

- Opening to the session and speakers introduction
- Dealing with mental health with a chronic condition

#### **Focus on Central and Eastern Europe**

- Svetoslava Stoyanova
- Youth Debate
  - o Debaters to be confirmed
- Q&A and session closure

#### **SLAMS**

#### 16.15-17.30 hrs

#### **Chaired by Nanda Uitslager (TBC) and Ana Boban**

- Opening to the session and speakers introduction
- Global assays
  - Yesim Dergaud
- Bleeding rates and pharmacokinetics
  - Laura Bukkems
- Inhibitor Immune response
  - Sebastien Lacroix Desmazes
- Art as a means to raising awareness the Slovenian experience for VWD in the community
  - Mitja Kavčič
- Slam topic to be confirmed
  - Speaker TBC
- Nordic walking as a means to increase physical activity in people with bleeding disorders
  - Josipa Belev



## **Conference Programme**Sunday, 8 October 2023

#### **Ageing and Bleeding Disorders**

09.00-10.00 hrs

#### **Chaired by Ivan Paclik and Kate Khair**

- Opening to the session and speakers introduction
- Managing co-morbidities in ageing
  - Robert Klamroth
- Managing co-morbidities patient perspective
  - Clive Smith
- Using anti-thrombotic medication in bleeding disorders
  - o Ana Boban
- A geriatrician's perspective
  - o William McKeown
- Q&A and session closure

**Conference closing and take-aways** 

12.25-12.55 hrs

Olivia Romero-Lux and Marko Marinić