

## 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
  - *Ana Boban*
- Quality of life of people with haemophilia in Croatia
  - *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
  - *Pratima Chowdary*
- Shared decision-making and advocating for care
  - *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
- Real World Evidence: VWD Patients Lived-Experience
  - *Fiona Brennan*
- Redefining needs
  - *Sunny Maini and Jo Traunter*
- Potential future therapies
  - *Michelle Lavin*
- Q&A and session closure

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### 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 Ana Pastor and Naja Skouw-Rasmussen

- Opening to the session and speakers introduction
- Improving diagnosis and care pathways
  - *Megan Brown*
- Engaging women - Ambassadors update
  - *Yannick Collé*
- Putting yourself first
  - *Karola Diósi*
- 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
  - *Pratima Chowdary*
- Current state of rebalancing agents
  - *Cedric Hermans*
- Bi-specific antibodies: Old, new, repurposed
  - *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
  - *David Stephenson*
- Pain and physiotherapy across Europe
  - *Paul McLaughlin*
- 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
  - *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 with focus on Central and Eastern Europe
  - *Svetoslava Stoyanova*
- Youth Debates
  - Whose agenda is it anyway? Gene therapy is on the horizon - *Daniel Simek and António Almeida*
  - Umbrella rare disease organisations vs national member organisations - *Ross Bennett and Stephan Meijers*
- Q&A and session closure

#### SLAMS

16.15-17.30 hrs

Chaired by **Nanda Uitslager** and **Ana Boban**

- Opening to the session and speakers introduction
- Global assays - *Yesim Dergaud*
- Inhibitor Immune response - *Sebastien Lacroix Desmazes*
- Mapping Haemophilia Care pathways - *Caroline Musser*
- TeamHaem goes green - *Claire Forde*
- Art as a means to raising awareness - the Slovenian experience for VWD in the community - *Mitja Kavčič*
- Mental health in Kyrgyzstan - *Aizat Aidarbekova*
- 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
  - *Ana Boban*
- A geriatrician's perspective
  - *William McKeown*
- Q&A and session closure

#### Conference closing and take-aways

12.25-12.55 hrs

Olivia Romero Lux and Marko Marinić