



# EHC Conference 2024 - Programme

Friday 4 October 2024

Grand Hotel Millennium, Sofia

9.00 - 9.30

## Bulgaria Opening Session

**Co-Chairs Miguel Crato, Toshko Lissitchkov**

Opening of the conference - Miguel Crato, Jordan Nedevski  
Bleeding disorder care in Bulgaria - Atanas Banchev, Toshko Lissitchkov

10.00 - 11.00

## All about platelets (ERIN)

**Co-Chairs Evelyn Grimberg, Maria Elisa Mancuso**

Small but important - Erica De Candia  
How to describe platelet in the lab? - Anna Pavlova  
Born with dysfunctional platelets - Amy Owen

11.00 - 11.30

## Coffee break

11.30 - 12.15

## Roche Symposium - Living a Normal Life by Preventing Joint Damage

12.15 - 13.15

## Lunch

13.15 - 14.00

## Novo Nordisk Symposium - Addressing Unmet Medical and Patient Needs in Haemophilia: Current Challenges and Aspirations

14.30 - 15.30

## Complex or just complicated (vWD)

**Co-Chair Manon Degenaar-Dujardin and Susan Halimeh**

Diagnosis is not the final destination - Baiba Ziemele  
New tests, old challenges - Annette Bowyer  
Core Outcome for vWD - Alberto Tosetto

15.30 - 16.00

## Coffee break

16.00 - 18.30

## EHC General Assembly

*Open to EHC NMOs and invited observers ONLY*

19.30 - 21.00

## Welcome dinner



9.00 - 10.00

**Clotting in pink (Women & BD)**

**Co-Chairs Ana Boban, Tatjana Markovic**

The different stages of women life - Sheila Radhakrishnan

Who cares of the carers? - Gaby Golan

I'd like to wear white - Evelyn Grimberg

10.15 - 11.45

**SLAMS**

**Co-Chairs Panagiotis Christoforou, Atanas Banchev**

Oral health as key component for good quality of life - Viktoriya Mandova

New opportunities in replacement therapy - Chris Koenigs

Patient perspective and expectations in GT - Yuliyana Marinova

How do we prevent joint damage nowadays - Roberta Guateriotti

Physio: what's new? - Paul McLaughlin

Treating Glanzmanns: A Nurses Perspective - Kate Khair

11.45 - 12.00

**Coffee break**

12.00 - 12.45

**Pfizer Symposium - Towards freedom: the impact of new therapies on mental health**

12.45 - 13.45

**Lunch**

13.45 - 14.30

**Sobi Symposium - Exploring the Optimal Balance in Life and Care With Haemophilia A: is Something Changing?**

15.00 - 16.00

**Let's talk about sex**

**Co-Chairs Jan Blatny, Stefan Radovanovic**

Sex as a part of quality of life - Tessa van Gastel

How to talk about sex? - Nanda Uitslager

Challenges in sex life for PBDs based on psychosocial data - Marko Marinic

16.00 - 16.30

**Coffee break**

16.30 - 17.30

**Youth Debate**

**Co-Chairs Admir Mehic, Brian O'Mahony**

Shared decision making in the era of AI - to use or not? - Alex Taylor Rose and Milovan Kumovic

Rare bleeding disorders and engagement from within the community - it is a national issue or a European one? - Leonidas Diamantopoulos and Samuel Compagnin

19.00 19.30

*Departure and transport*

19.45 - 00.00

*Conference dinner*



**EHC Conference 2024- Programme**  
Sunday 6 October 2024

Grand Hotel Millennium, Sofia

**09.00 - 10.00**

**My family is beside me**

**Co-Chairs Christina Burgess, Panagiotis Christoforou**

Family support is a team work - Christina Burgess

Parents discussion - Olivia Romero-Lux, Cathy Verbraeken, Jim O'Leary , Panagiotis Christoforou, Christina Burgess

**10.30 - 11.00**

**PROBE as Quality-of-Life tool for Advocacy through Real-World Experience**

Panelists:

Mark W. Skinner

Brian O'Mahony

Nyrber Orozaliev

Baiba Ziemele

Alexandra (Sasha) Kucher

Facilitator: Fiona Brennan

**11.00 - 11.30**

**Coffee break**

**11.30 - 12.45**

**Community Session**

**12.45 - 13.15**

**The grand finale & take-aways**

**Co-Chairs Jordan Nedevski, Thomas Schindl, Miguel Crato**

**13.15 - 14.00**

**Take away Lunch**