



ROUND TABLE

No Patient Left Behind: Unmet Needs in Extremely Rare Bleeding Disorders

17 March 2025, 14:00-16:00 CET

European Parliament

Brussels, Belgium

PROGRAMME

13:30-14:00

Registration

14:00-14:10

Welcome and introduction

Miguel Crato, EHC President

MEP Tomislav Sokol (EPP, Croatia)

14:10-14:20

Rare Diseases in EU Policy

MEP Tomislav Sokol (EPP, Croatia)

14:20-14:40

**Extremely Rare Bleeding Disorders: A Joint Look at
Unmet Needs**

Maria Elisa Mancuso, EHC Medical Advisory Group

Katharina Holstein, EAHAD Very Rare Coagulation Factor

Deficiencies Working Group

14:40-15:00

Living with an Extremely Rare Bleeding Disorder

Nathan Roubaty

Inge Peters

15:00-15:10

**The European Rare Inhibitor Network: Building
Knowledge, Pathways and Hope**

ERIN Committee

15:10-15:40

Panel discussion

Clinician

Marina Pimentel

DG Research, European Commission (TBC)

ERN-EuroBloodNet (TBC)

15:40-15:50

Q&A and discussions

15:50-16:00

Conclusions and closing

MEP Tomislav Sokol (EPP, Croatia)

Miguel Crato, EHC President