

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 <i>Miguel Crato, EHC President MEP Tomislav Sokol (EPP, Croatia)</i>
14:10-14:20	Rare Diseases in EU Policy <i>MEP Tomislav Sokol (EPP, Croatia)</i>
14:20-14:40	Extremely Rare Bleeding Disorders: A Joint Look at Unmet Needs <i>Maria Elisa Mancuso, EHC Medical Advisory Group Katharina Holstein, EAHAD Very Rare Coagulation Factor Deficiencies Working Group</i>
14:40-15:00	Living with an Extremely Rare Bleeding Disorder <i>Nathan Roubaty Inge Peters</i>
15:00-15:10	The European Rare Inhibitor Network: Building Knowledge, Pathways and Hope <i>ERIN Committee</i>

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