

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

Patient 1

Patient 2

15:00-15:10

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

ERIN Committee

<p>15:10-15:40</p>	<p>Panel discussion</p> <p>Clinician Patient</p> <p>Stephane Hogan, DG Research, European Commission (TBC)</p> <p>Béatrice Gulbis, Co-coordinator, ERN-EuroBloodNet (TBC)</p>
<p>15:40-15:50</p>	<p>Q&A and discussions</p>
<p>15:50-16:00</p>	<p>Conclusions and closing</p> <p><i>MEP Tomislav Sokol (EPP, Croatia)</i></p> <p><i>Miguel Crato, EHC President</i></p>