



ROUND TABLE

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

17 March 2026, 14:00-16:00 CET
ITALY Room, THON EU Hotel
Brussels, Belgium

PROGRAMME

| | |
|-------------|---|
| 13:30-14:00 | Registration |
| 14:00-14:10 | Welcome and introduction <i>Tatjana Marković, EHC Vice-President</i> |
| 14:10-14:20 | Rare Diseases in EU Policy <i>MEP Tomislav Sokol (EPP, Croatia) (video message)</i> |
| 14:20-14:40 | Extremely Rare Bleeding Disorders: A Joint Look at Unmet Needs <i>Maria Elisa Mancuso, EHC Medical Advisory Group</i> <i>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</i> <i>Inge Peters</i> |
| 15:00-15:10 | The European Rare Inhibitor Network: Building Knowledge, Pathways and Hope <i>Maja Johanne Søndergaard Knudsen, ERIN Committee</i> |

15:10-15:40

Panel discussion

Cédric Hermans, Head of Division of Haematology, the Saint-Luc University Hospital
Marina Pimentel, Patient
Maria Elisa Mancuso, EHC Medical Advisory Group

15:40-15:50

Q&A and discussions

15:50-16:00

Conclusions and closing

Tatjana Marković, EHC Vice-President