

6th November 2025



ERN | EuroBloodNet

7th Progress Meeting

Current status and new actions over the last year

Coordination team:



Pierre Fenaux – Coordinator & Chair of oncological hub



Béatrice Gulbis – Co-coordinator & Chair of non-oncological hub



María del Mar Mañú Pereira – Scientific Director & ENROL Coordinator



Alba Albert Robledo – Scientific manager



Mariangela Pellegrini – Manager for Health Policy, Education & Patient Engagement

7th PROGRESS MEETING

Opening plenary session

13:00 13:10 Welcome & Agenda – Pierre Fenaux (AP-HP – Saint Louis, Paris) & **Béatrice Gulbis** (H.U.B. Hôpital Erasme – ULB, Brussels)

13:10 14:10 ERNs & Joint Partnerships – Chair: Maria del Mar Mañú Pereira (ERN CG vice-chair, Vall d'Hebron University Hospital, Barcelona)

- **ERNs State of play – Maria del Mar Mañú Pereira** (ERN CG vice-chair, Vall d'Hebron University Hospital, Barcelona)
- **ERNs WG on knowledge generation and capacity. Subgroup on AI and RDs – Stefano Vettorazzi** (Policy Officer European Commission, co-chair of the ERNs Knowledge Generation and Capacity WG, Brussels)
- **Clinical research networks (ERDERA) – Cécile Ollivier** (ERDERA, WP9 co-chair, Critical Path Institute, Netherlands).

14:10 14:30 Questions & Discussion

ERN-EuroBloodNet website navigation session

Chair: Alba Albert Robledo (Vall d'Hebron University Hospital, Barcelona)

14:30 14:50 ERN-EuroBloodNet website Daiana N. Lopez (Vall d'Hebron University Hospital, Barcelona)

Clinical Practice Guidelines & Access to Highly Specialized Care

Chair: Alba Albert Robledo (Vall d'Hebron University Hospital, Barcelona)

14:50 15:05 ERN-EuroBloodNet New CPGs/CDSTs produced by the ERN – example on SCD Béatrice Gulbis (H.U.B. Hôpital Erasme – ULB, Brussels)

15:05 15:20 Best Practices for Patients with a focus on the charter for optimal care transitions from pediatric to adult care in Sickle Cell Disease -

Mariangela Pellegrini (AP-HP – Hôpital Saint Louis, Paris)

15:20 15:35 Questions & Discussion

Education

Chair: **Pierre Fenaux** (AP-HP – Saint Louis, Paris) & **Mariangela Pellegrini** (APHP – Saint Louis, Paris).

15:35 15:50 Educational actions

- **Overview for ERN-EuroBloodNet actions for health professionals and patients - Mariangela Pellegrini** (AP-HP – Saint Louis, Paris)

15:50 15:57 Collaborative programs for education on research

- **EDIT-SCD – webinar’s program on Gene editing - Annarita Miccio** (Institut imagine, Paris)

15:57 16:10 Questions & Discussion

CPMS

Chair: **Béatrice Gulbis** (H.U.B. Hôpital Erasme – ULB, Brussels)

16:10 16:20 CPMS 2.0 - Christophe Goetghebuer (H.U.B. Hôpital Erasme – ULB, Brussels)

16:20 16:40 Questions & Discussion

Registries & clinical outcome research

Chairs: **Maria del Mar Mañú Pereira** (Vall d’Hebron University Hospital, Barcelona).

16:40 17:00 The future of data sharing in EU

- **ENROL contribution to Epidemiology surveillance & Data driven research**
 - **ENROL Registry Module for the Collection of annual counts of RHDs patients (EpiBlood) – Sara Reidel** (Vall d’Hebron University Hospital, Barcelona).

- **ENROL supporting RHD RWD standardization to advance research collaboration** – **Maria del Mar Mañú Pereira** (Vall d'Hebron University Hospital, Barcelona).

17:00 17:10 Questions & Discussion

Clinical Trials

Chair: **Pierre Fenaux** (AP-HP – Saint Louis, Paris)

17:10 17:17 ERN-EuroBloodNet sponsoring Clinical Trials and promoting innovative therapies – **Pierre Fenaux** (AP-HP – Saint Louis, Paris)

17:17 17:24 Mitapivat in hereditary anemias (SATISFY) – **Thomas Doeven** (University Medical Center Utrecht, Utrecht, Netherlands).

17:24 17:30 Questions & Discussion

Closing

Legend:

AI: Artificial Intelligence

CPGs/CDST: Clinical Practice Guidelines and Clinical Decision Supporting Tools

CPMS: Clinical Patient Management System

EDIT-SCD: Assessing efficacy and safety of genome EDITing approaches for Sickle Cell Disease

EHA: European Hematology Association

ENROL: European Rare Blood Disorders Platform

ERDERA: European Rare Diseases Research Alliance

RDs: Rare Diseases

RHD: Rare Hematological Diseases

RWD: Real World Data

SCD: Sickle Cell Disease

WG: Working group

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