



ERN-EuroBloodNet and ENROL Registry:

Boosting data driven research and innovative therapies & fostering best practices and access to highly specialized care

Friday 13th June 2025 – 13:00-16:00 (CEST)

**EHA Congress,
Allianz MiCo, Milano Convention Centre
Room Sky 2 - Hall 2**



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network
Hematological
Diseases (ERN EuroBloodNet)

Coordination team:

Pierre Fenaux – ERN Coordinator & Chair of oncological hub
Béatrice Gulbis – ERN Co-coordinator & Chair of non-oncological hub
María del Mar Mañú Pereira – ERN Scientific Director & ENROL Coordinator
Alba Albert Robledo – Scientific Manager
Mariangela Pellegrini – Educational & Patients Program Manager
Giulio Sannasardo – Project Manager
Daiana Natali Lopez – Dissemination Manager



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Agenda

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Welcome session: Overview of ERN actions

13:00 **13:15** ***María del Mar Mañú Pereira*** (*Vall d'Hebron University Hospital / Vall d'Hebron Research Institute, Barcelona*)

Session 1: ERN-EuroBloodNet Clinical and Data driven research

Chaired by *Pierre Fenaux* (*AP-HP, Hôpital Saint Louis*) and ***María del Mar Mañú Pereira*** (*Vall d'Hebron University Hospital / Vall d'Hebron Research Institute, Barcelona*)

13:15 **13:30** **ERN-EuroBloodNet sponsored clinical trials**
Pierre Fenaux (*AP-HP – Hôpital Saint Louis*)
Eduard van Beers (*University Medical Center Utrecht*)

14:30 **14:10** **Role of ERN Registries in advanced research in hematology**
Sara Reidel (*Vall d'Hebron University Hospital / Vall d'Hebron Research Institute, Barcelona*)

GenoMed4All & SYNTHEMA AI Federated Platforms in hematology
Federico Álvarez (*Universidad Politécnica de Madrid*)

AI Federated platform in oncology
Matteo Della Porta (*IRCCS Clinical Institute Humanitas di Rozzano*)

AI Federated platform in anemia
María del Mar Mañú Pereira (*Vall d'Hebron University Hospital/ Vall d'Hebron Research Institute, Barcelona*)

Radiomics in Sickle Cell Disease
Raffaella Colombatti (*Azienda Ospedale – Università Padova*)

14:10 **14:30** **Open discussion**
14:30 **14:45** **Break in the room**



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Session 2: Clinical Practice Guidelines (CPGs) & Clinical Decision Support Tools (CDSTs)

Chaired by Luca Malcovati (Foundation IRCCS Polyclinic San Matteo, Pavia) **Sabine Blum** (Lausanne University Hospital, Switzerland), **Béatrice Gulbis** (H.U.B. Hôpital Erasme – ULB, Brussels)

14:45 14:55 **ERN-EuroBloodNet Repository of CPGs/CDSTs**
Luca Malcovati (Foundation IRCCS Polyclinic San Matteo, Pavia)

14:55 15:35 **ERN-EuroBloodNet New CPGs/CDSTs produced by the ERN**

Diagnosis and treatment of Burkitt lymphoma in adults: clinical practice guidelines from ERN-EuroBloodNet
Vincent Ribrag (Gustave Roussy, Paris)

ERN-EuroBloodNet Recommendations on Sickle Cell Disease
Béatrice Gulbis (H.U.B. Hôpital Erasme – ULB, Brussels)

EHA/ERN-EuroBloodNet Recommendations on Rare Hemolytic Anaemia
Richard van Wijk (University Medical Center Utrecht)

Clinical practice guidelines on Vexas Syndrome endorsed by ERN-Eurobloodnet
Pierre Fenaux (AP-HP – Hôpital Saint Louis)

Designing Patient-Centered Care: Patient Journeys from Educational Programs and Patient Versions of Guidelines. Pilot of von Willebrand Disease and Burkitt Lymphoma
Mariangela Pellegrini (AP-HP – Hôpital Saint Louis)

15:35 16:00 **Open discussion**

Closing



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Legend:

AI: Artificial Intelligence

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

[ENROL](#): European Rare Blood Disorders Platform

ERN: European Reference Network

[GenoMed4All](#): Genomics and Personalized Medicine for all through Artificial Intelligence in Hematological Diseases

MDS-RIGHT: Providing the right care to the right patient with MyeloDysplastic Syndrome at the right time

MoU: Memorandum of Understanding

[RADeep](#): Rare Anaemia Disorders European Epidemiological Platform

RHD-CDS: Rare Hematological Diseases Common Data Set

[SYNTHEMA](#): Synthetic generation of hematological data over federated computing frameworks



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