



Board of the Network Meeting

12 June, 2026

EHA Congress

Stockholmsmässan, Stockholm, Sweden,

Room K21 (auditorium)



**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 Coordinator & ENROL Registry coordinator
Alba Albert Robledo – ERN Scientific Manager
Mireia Arnedo Valero – ERN Policy Manager
Giulio Sannasardo – ERN Project Manager
Daiana Natali Lopez – ERN Dissemination Manager
Hiba Fadlallah – ERN Education & Patients Program Manager
Kathleen Weatherly – ERN Education for Health Professionals and CPMS Manager
Raquel Mosull del Campo – ERN and ENROL Project and Financial Manager
Firdaous El Khattab – ERN Financial and Administrative officer
Sarah Wambacq – ERN Project Manager



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Agenda

12th June 2026



08:45 09:00 Attendee Check-in and Seating

SESSION 1: EU ACTION PLAN FOR RARE DISEASES

09:00 09:30 **Present and future of the ERNs: HLM4Rare & the European Cancer Mission**
María del Mar Mañú Pereira (*Vall d'Hebron Institut de Recerca (VHIR), Vall d'Hebron Hospital Universitari, Barcelona, Spain*)
Matteo Della Porta (*IRCCS Clinical Institute Humanitas di Rozzano, Italy*)
Angelo Loris Brunetta (*Thalassaemia International Federation (TIF), Genoa, Italy*)

09:30 09:40 **ERN-EuroBloodNet Action Plan and Governance**
María del Mar Mañú Pereira (*Vall d'Hebron Institut de Recerca (VHIR), Vall d'Hebron Hospital Universitari, Barcelona, Spain*)

09:40 09:45 **Questions & Answers**

09:45 10:05 **Workforce development & capacity building for rare diseases. ERN infrastructure on education for patients and professionals & best practices**
Béatrice Gulbis (*H.U.B. Hôpital Erasme – ULB, Brussels*)
Domenico Girelli (*Azienda Ospedaliera Universitaria Integrata (AOUI) Verona, Italy*)
Miriam Santos Freire (*Associação Portuguesa de Pais e Doentes com Hemoglobinopatias (APPDH), Portugal*)

10:05 10:10 **Questions & Answers**

10:10 10:30 **Equitable access to diagnostics and early treatment**
María del Mar Mañú Pereira (*Vall d'Hebron Institut de Recerca (VHIR), Vall d'Hebron Hospital Universitari, Barcelona, Spain*)
Sophie Susen (*CHU de Lille, France*)
Ioanna Todorova (*Bulgarian Thrombotic thrombocytopenic purpura patient organization, Bulgaria*)

10:30 10:35 **Questions & Answers**

Coffee break 15'

- 10:50 11:10 EU Leadership in Clinical Trials & equitable access to innovative therapies**
Pierre Fenaux (*Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis, France*)
Eduard van Beers (*University Medical Center Utrecht, The Netherlands*)
- 11:10 11:20 Optimizing Treatment and Assessing Quality of Life for Patients**
Giovanni Martinelli (*University of Bologna Dipartimento di Scienze Mediche e Chirurgiche (DIMEC), Italy*)
- 11:20 11:25 Questions & Answers**
- 11:25 11:35 Integration of the ERN into the National care and research system: Italy**
Raffaella Colombatti (*Azienda Ospedale – Università Padova, Italy*)
- 11:35 11:45 Integration of the ERN into the National care and research system: Belgium**
Béatrice Gulbis (*H.U.B. Hôpital Erasme – ULB, Brussels, Belgium*)
- 11:45 11:50 Questions & Answers**
- 11:50 12:00 Boost real world evidence generation**
María del Mar Mañú Pereira (*Vall d'Hebron Institut de Recerca (VHIR), Vall d'Hebron Hospital Universitari, Barcelona, Spain*)
David-Zacharie Issom (*Association Suisse Drepano, Switzerland*)
- 12:00 12:05 AI & synthetic data generation**
Matteo Della Porta (*IRCCS Clinical Institute Humanitas di Rozzano, Italy*)
- 12:05 12:10 Questions & Answers**

SESSION 2: ERN ACTION PLAN FOR RARE HEMATOLOGICAL DISEASES

Session moderators: **Béatrice Gulbis** and **María del Mar Mañú Pereira**.

- 12:10 12:45 Panelists**
- Paola Bianchi** (*Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic – Milan, Italy*)
Angelo Loris Brunetta (*Thalassaemia International Federation - Associazione Ligure Talassemici Onlus, Italy*)
Matteo Della Porta (*IRCCS Clinical Institute Humanitas di Rozzano, Italy*)
Pierre Fenaux (*Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis, France*)
Flora Peyvandi (*Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic – Milan, Italy*)