

3rd ERN-EuroBloodNet Board of the Network meeting

13th and 14th November 2019, Barcelona

Vall d'Hebron University Hospital

Conference Hall - Teaching Pavilion UAB
(Sala d'Actes – Pavelló Docent UAB)



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
Victoria Gutiérrez Valle – IT and dissemination manager
Mariangela Pellegrini – ERN manager



Co-funded by
the European Union

Agenda

Wednesday 13th November

08:45 – 9:30 Registration

09:30 – 09:50 Welcome - P Fenaux & B Gulbis. ERN-EuroBloodNet Coordinators

Plenary session: ERNs consolidation & sustainability. Chaired by P Fenaux & B Gulbis

09:50 – 10:10 Impact of ERNs at Hospital level and national health systems – Y Cossio. Director of Information Systems in Vall d'Hebron Barcelona Hospital Campus.

10:10 – 10:30 ERNs consolidation and long-term sustainability – E Terol. DG SANTE-European Commission

10:30 – 10:50 European Joint Programme (EJP) on Rare Diseases and link with ERNs – C Carta. Istituto Superiore di Sanità, EJP WP14 leader “Training on data management & quality”

10:50-11:10 Round table: What do we expect from ERNs in long term?

11:10 – 11:30 Coffee Break

Parallel session I: Cross border health, interprofessional consultations and Webinars program

11:30 – 12:30 Introduction to Parallel session I

- EuroBloodNet new experts profiles and disease grouping relevance for cross border health and interaction with stakeholders - MM Mañú Pereira
- Pilot case for cross border Bone marrow transplant on non-oncological diseases among two EuroBloodNet members – R Colombatti
- Clinical Patient Management System (CPMS): expert panels for cross border advice – B Gulbis
- Webinars programme for patients and health professionals – P Aguilar-Martinez and D Bron
- External Quality Assessment for rare haematological diseases – B de la Salle

12:30 – 13:30 Parallel session I – Discussion by Areas of expertise

Audience will be divided by areas of expertise into parallel sessions for discussion and answer of key questions provided by the speakers, who will rotate among the different groups for identifying the points of view from the different areas of expertise.

13:30 – 14:30 Lunch (14:20 Family photo)

14:30 – 15:30 Outcomes from Parallel session I and discussion

MM Mañú Pereira, R Colombatti, B Gulbis, P P Aguilar-Martinez, D Bron and B de la Salle will provide a summary of main points discussed in the different areas of expertise.

15:30-16:30 ERN and members assessment based on monitoring indicators

16:30 – 17:00 Closing remarks

Thursday 14th November

09:00 – 9:20 Registration

09:20 – 09:30 Welcome 2nd day – P Fenaux & B Gulbis. ERN-EuroBloodNet Coordinators

09:30 – 10:00 Update on ERN WGs Guidelines and Research – MM Mañú Pereira

Parallel session II: Registries, clinical trials, best practices and patients actions

10:00 – 11:00 – Introduction to Parallel session II

- EuroBloodNet proposal for rare hematological diseases (ENROL) - MM Mañú Pereira and B Gulbis
- EuroBloodNet sponsoring Clinical trials – P Fenaux
- Inventory of guidelines and assessment of implementation – L Malcovati
- Short stays for health professionals – M Pellegrini
- Patients activities – M Pellegrini and A Weinman

11:00 – 11:30 Coffee Break

11:30 – 12:30 Parallel session II – Discussion by Areas of expertise

Audience will be divided by areas of expertise into parallel sessions for discussion and answer of key questions provided by the speakers, who will rotate among the different groups for identifying the points of view from the different areas of expertise.

12:30 – 13:30 Outcomes from Parallel session II

MM Mañú Pereira, B Gulbis, P Fenaux, L Malcovati, M Pellegrini and A Weinman will provide a summary of main points discussed in the different areas of expertise.

13:30 – 14:00 Closing remarks and taking home messages

14:00 – 15:00 Lunch & Departures