



Closing meeting – 1st phase of the project Wednesday 3rd of May 2023



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)

Coordination team:

María del Mar Mañú Pereira - Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)

Victoria Gutiérrez Valle - Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)

Claire Diot - Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)

Sara Reidel - Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)

Béatrice Gulbis - Université Libre de Bruxelles/Hôpital ERASME (ULB/ERASME)

Ines Labidi - Hôpital Universitaire des Enfants Reine Fabiola (HUDERF)

Petros Kountouris - The Cyprus Foundation for muscular dystrophy research (CING)

Stella Tamana - The Cyprus Foundation for muscular dystrophy research (CING)

Froso Sophocleous - The Cyprus Foundation for muscular dystrophy research (CING)

Pierre Fenaux - Assistance Publique - Hôpitaux de Paris, Hôpital Saint-Louis (AP-HP)

Mariangela Pellegrini - Assistance Publique - Hôpitaux de Paris, Hôpital Saint-Louis (AP-HP)



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Agenda

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14:00-14:10: Welcome message and Introduction - María del Mar Mañú Pereira, Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)

14:10-14:35: Harnessing the power of Health data at European level:

- EU-RD Platform - Andri Papadopoulou, *EC Joint Research Centre*
- Rare Disease partnership and European Health Data Space - Franz Schaefer, *coordinator of the European Rare Kidney Disease Reference Network (ERKNet), Heidelberg University Hospital*

14:35-15:10: Setting up the European Rare Blood Disease Platform (ENROL)

- Governance - Béatrice Gulbis, *Université Libre de Bruxelles/Hôpital ERASME (ULB/ERASME)*
- Legal frame for re-sharing of data - Claire Diot-Lefebvre, *Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)*
- Facilitating epidemiological surveillance, research and access to new treatments for RHD: ENROL CRF and Research questions - María del Mar Mañú Pereira, *Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)*
- Technical implementation: demo platform - Petros Kountouris, *The Cyprus Foundation for muscular dystrophy research (CING)*

15:10-16:10: ENROL, a tool to advance research

- RADeep, Rare Anaemia - Béatrice Gulbis, *Université Libre de Bruxelles/Hôpital ERASME (ULB/ERASME)*
- EU Blast, European Blastic plasmacytoid dentritic cell neoplasm Network - Erick Deconinck, *CHRU Besançon*
- TWIST, Von Willebrand disease - Sophie Susen, *CHU Lille*
- Impact AML - Giovanni Martinelli, *Istituto Romagnolo per lo Studio dei Tumori "Dino Amadori"*
- GenoMed4All / Synthema :
 - SCD - María del Mar Mañú Pereira, *Vall d'Hebron, University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH)*
 - MdS - Matteo Della Porta, *IRCCS Clinical Institute Humanitas - Rozzano*

16:10-16:25: ENROL and patients involvement - Mariangela Pellegrini, *Assistance Publique - Hôpitaux de Paris, Hôpital Saint-Louis (AP-HP)*

16:25-17:00: Conclusion & Next step