

enrol

European Rare Blood
Disorders Platform

ENROL CLOSING MEETING



European
Reference
Network

Hematological
Diseases (ERN EuroBloodNet)



Co-funded by
the European Union

This document was funded by the European Union's Health Programme (2014-2020). The content of this document represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

The European Rare Blood Disorders Platform (ENROL) is the pan-European patient registry of the European Reference Network ERN-EuroBloodNet, aiming at grouping sufficient data of patients affected by rare haematological diseases in order to promote research and perform epidemiological surveillance.

During the first 3 years of its implementation, the ENROL registry has been co-funded by the European Commission and led by a European Consortium composed of :

- Vall d'Hebron University Hospital (HUVH) - Vall d'Hebron University Hospital Foundation - Research Institute (VHIR), Spain - Principal Investigator: Maria del Mar Mañú Pereira, Coordinator ;
- Hôpital Erasme - Université Libre de Bruxelles (ERASME / LHUB-ULB), Belgium - Principal Investigator: Béatrice Gulbis;
- The Cyprus Institute of Neurology and Genetics (CING), Cyprus - Principal Investigator: Petros Kountouris ;
- Assistance Publique - Hôpitaux de Paris (AP-HP), Hôpital Saint-Louis, France - Principal Investigator: Pierre Fenaux

A closing meeting was organised to wrap up the first phase of the project, finalising on 31st of May. One hundred participants, including physicians, patients associations' representatives, and institutional stakeholders, from 15 EU Member States participated, showing the growing interest for this initiative.

Over the course of this half day online meeting, an overview of the extensive work done so far was presented:

As it can be challenging to gather sufficient data from rare disease patients, ENROL developed a strategy to connect and facilitate the upgrade of existing rare haematological diseases registries in Europe, while promoting the building of new ones when / where lacking.

Following this strategy, ENROL managed to:

- **Connect with RADeep**, the Rare Anaemia Disorders European Epidemiological Platform.
- **Promote the creation of 2 new sub-registries** in 2 domain specific areas :
 - **EU-Blast**: European Blastic Plasmacytoid Dendritic Cell Neoplasm Network
 - **TWIST**: von Willebrand Disease

In addition, ENROL positioned itself as a key player in Europe for strengthening the use and re-use of health data on rare haematological diseases for the provision of best healthcare and research, by collaborating with following EU funded projects linked to the re-use of patients data :

- **IMPACT-AML**: Master Framework and Pragmatic Clinical Trial for Relapse or Refractory Acute Myeloid Leukemia, coordinated by Giovanni Martinelli at IRCCS Istituto Romagnolo per lo Studio dei Tumori "Dino Amadori" -IRST S.r.l. in Italy
- **GenoMed4ALL**: Genomics and Personalized Medicine for all through Artificial Intelligence in Haematological Diseases coordinated by Federico Álvarez from Universidad Politecnica Madrid (Spain) (use cases: Sickle Cell Disease, and Myelodysplastic syndromes)
- **SYNTHEMA**: Synthetic generation of haematological data over federated computing frameworks coordinated by Federico Álvarez from Universidad Politecnica Madrid (Spain) (use cases: Sickle Cell Disease and Myelodysplastic syndromes)

In the next phase of its implementation, ENROL will continue the collection of data, but also share data (anonymised and pseudonymised patient-level data) with allowed third parties in order to provide to researchers and stakeholders the opportunity to benefit from the work done. A Data Access Committee (DAC) has been established and will assess data requests.

We are confident the next phase of the ENROL project will contribute to improving the life and condition of patients in Europe affected by rare haematological diseases!

More information on ENROL is available at the following link: [What is ENROL? | ENROL | EuroBloodNet](#)

