

The European Rare Blood **Disorders** Platform

Gutierrez-Valle V^{* 1}, Gulbis B², Kleanthous M³, Kountouris P³, Tamana S³, Pellegrini M⁴, Fenaux P⁴, Mañú-Pereira MM¹ ¹ Vall d'Hebron Research Institute- University Hospital Vall d'Hebron, Barcelona, Spain, ²Hôpital ERASME/LHUB-ULB, Brussels, Belgium, ³Cyprus Institute of Neurology and Genetics, Nicosia, Cyprus, ⁴AP-HP, Hôpital Saint Louis, Paris, France

What is ENROL?

ENROL has been conceived in the core of ERN-EuroBloodNet as an umbrella for both new and already existing registries on rare hematological diseases (RHD).

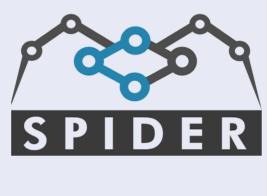
ENROL is endorsed by the European Hematology Association



To enable EU RHD Surveillance for Health planning and engagement of basic and clinical research

To connect, upgrade and build EU - RHD Registries by promoting interoperability standards (EU-RD Platform) and use of SPIDER pseudonymisation tool

> CONNECTING REGISTRIES

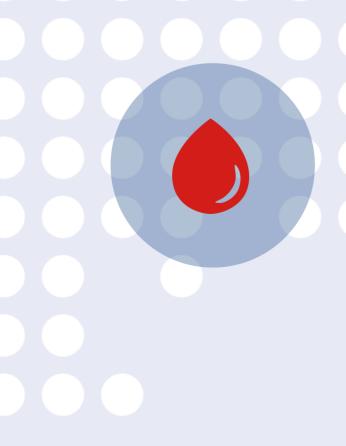


To create an interoperable and modular platform for integration of available data sources

PROMOTING EPIDMIOLOGICAL SURVEILLANCE AND RESEARCH

INTEROPERABLE PLATFORM

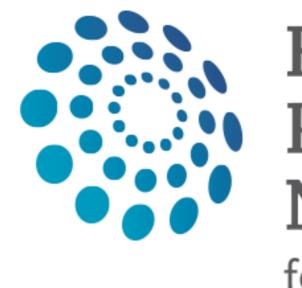
ENROL Consortium



Coordinator Dr Maria del Mar Mañú Pereira Vall d'Hebron University Hospital Foundation - Research Institute (VHIR) - Vall d'Hebron University Hospital (HUVH), Barcelona, Spain







European Reference Network

for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)

Collaboration with EURORDIS and European Patient Advocacy Groups (ePAGs)



ENROL Policy: Revision of ethical templates including Informed Consent

Collaboration with EURORDIS and ePAGs

Prof. Béatrice Gulbis Erasme University Hospital (ERASME) / LHUB-ULB, Brussels, Belgium



Prof. Marina Kleanthous The Cyprus Foundation for muscular dystrophy research (CING), Nicosia, Cyprus



Education: - Identification of 7 topics for Webinars sessions for patients - Selection of final topics and speakers

EURORDIS



Awareness: Dissemination for making patients and families aware about the benefits of participating in registries



Prof Pierre Fenaux Assistance Publique -Hopitaux de Paris (AP-HP), Paris, France

www.eurobloodnet.eu/enrol



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