# **EuroBleedNe**



# European Reference Network in Rare Hematological Diseases

1<sup>st</sup> year of implementation

ERN-EuroBloodNet, coordinated by Prof. Fenaux and cocoordinated by Prof. Gulbis, results from a joint effort of the European Hematology Association (EHA), the European Network for Rare and Congenital Anaemias (ENERCA) and European hematology patient organizations represented in the European Patient Advocacy Groups (ePAGS). 66 Healthcare providers from 15 Member States are the members of ERN-EuroBloodNet. Overall coordination is rotational in eaual periods of time between the two oncological and non-oncological hubs.

Five specific objectives were identified and linked to specialized Transversal Fields of Action (TFA) for the establishment of the annual work plan aiming to improve the delivery of care to patients affected by Rare Hematological Diseases (RHD). Main results from the 1st year of implementation are:



TFA on Crossborder Health

- Mapping of services available in Europe:
- Implementation of ORPHA classification for RHD at the website back office
- Creation of the dynamic inventory of ERN-EuroBloodNet members and multidisciplinary teams - 181 experts profiles and 220 departments profiles already created **Deliverable 3 - Report on ERN-EuroBloodNet members**

activity/facilities for RHD health provision

### **TFA on Best practices**

and heme synthesis

Create a comprehensive public database of reliable evidence based guidelines

- Creation of a list of international guidelines
- Definition of the protocol for the repository **Deliverable 4- Protocol for** creation of the repository of reliable guidelines

#### Innovative therapies Foster European cooperation in highly specialized procedures for diagnosis, innovative treatments and

research

#### TFA on Telemedicine

TFA on Clinical Trials and

Promote the creation of a

rare anaemias in

**Deliverable 7 - Report on** 

existing registries for RHD

affected by a RHD

**European registry of patients** 

Analysis of the state of the

art of existing registries for

collaboration with RADeep

research

Interprofessional consultation through the Clinical Patient Management System (CPMS) developed by the EC:

- Participation in the CPMS pilot phase
- CPMS analysis in the context of the **General Data Protection** Regulation

**Deliverable 6- Report on legal issues** on inter-professional consultation of complex cases

# **EuroBleedNet**

www.eurobloodnet.eu

## Inter profesional

consultation Provide inter-professional consultation by sharing of expertise and safe exchange of clinical information

medical education Facilitate continuing medical education and disseminate cutting-edge knowledge in the field of RHD

**Best practices** 

Promote best practices in

prevention, diagnosis and

Europe

#### **TFA on Continuing Medical Education** Elaboration of a multi annual educational programme

- Co-organization with EHA and the ePAGs of European symposia Identification of different
- strategies for gathering educational gaps

**Deliverable 5- Report on actions** foreseen by educational bodies (EHA and ESH) to address GAPS identified in annual educational programme

> Removing barriers for making highly specialized services available to everyone



1st year of ERN EuroBloodNet implementation has provided with excellent results to establish the basis for the next annual work plan

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#### highly specialized healthcaredelivery for **RHD** accross EU

# safe clinical care across

**Equal Access** 

Improve equal access to

Continuing