

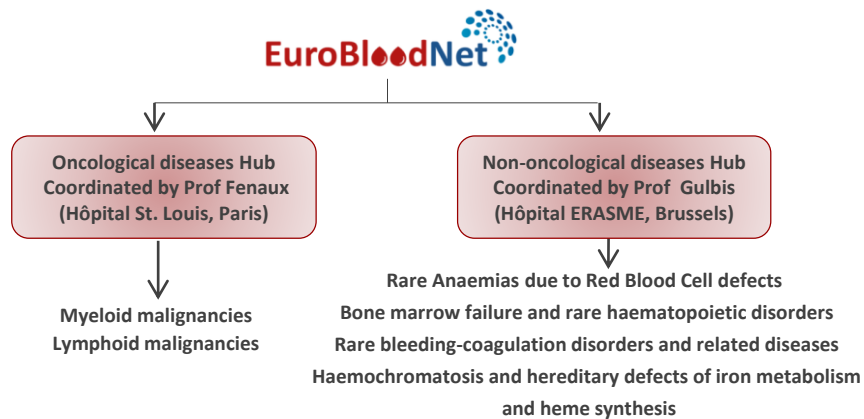


## European Reference Network in Rare Hematological Diseases

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

ERN-EuroBloodNet, coordinated by Prof. Fenaux and co-coordinated 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 equal 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 Clinical Trials and research

Promote the creation of a European registry of patients affected by a RHD

- Analysis of the state of the art of existing registries for rare anaemias in collaboration with RADeep

Deliverable 7 - Report on existing registries for RHD

### TFA on Telemedicine

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

### TFA on Best practices

Create a comprehensive public database of reliable evidence based guidelines

- Creation of a list of international guidelines
- Definition of the protocol for the repository

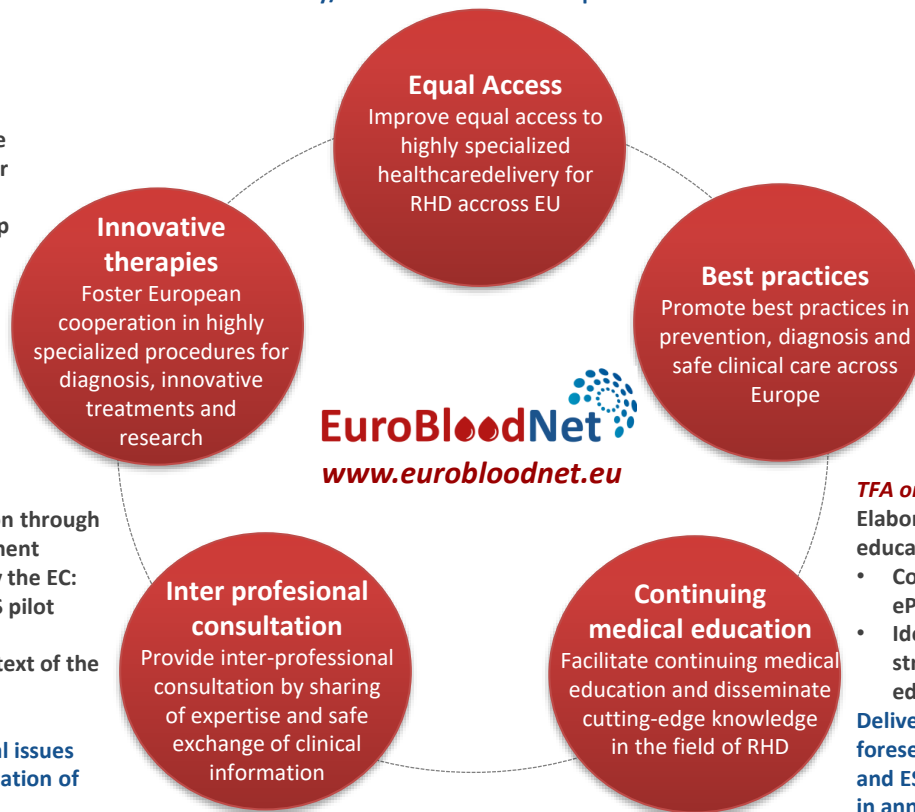
Deliverable 4- Protocol for creation of the repository of reliable guidelines

### 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



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

Removing barriers for making highly specialized services available to everyone

