

THE MAIN HUBS OF ERN-EUROBLOODNET COORDINATION

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If you are a patient, a patient care giver or a professional dealing with rare hematological diseases, contact us,
ERN-EuroBloodNet is working to assist your needs!



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The European Reference Network on Rare Hematological Diseases

Individuals and institutions committed to improving
healthcare services in rare hematological diseases



ERN-EuroBloodNet is a collaborative network aiming to **improve the healthcare services of complex or rare hematological diseases (RHD) and conditions that require highly specialized treatment in Europe.**

ERN-EuroBloodNet disease coverage involves **more than 450 RHDs according to ORPHA classification** encompassing oncological (for adult patients) and non-oncological diseases (for adult and pediatric patients).

THE DISEASE COVERAGE DIVIDED INTO 6 MEDICAL AREAS, SO CALLED SUBNETWORKS

ONCOLOGICAL HUB

- Myeloid malignancies
- Lymphoid malignancies

NON-ONCOLOGICAL HUB

- Rare red blood cell defects
- Bone marrow failure and hematopoietic disorders
- Rare bleeding-coagulation disorders and related diseases
- Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis

Methodological approach of ERN-EuroBloodNet shaped in accordance with ongoing EU activities, contributing to innovative, efficient and sustainable health systems and facilitating the access to a better and safer healthcare for EU citizens. **In accordance with the Directive on Cross-Border Healthcare (2011/24/EU), our efforts are undertaken to improve the delivery of cross-border care to RHD patients.**

WE HAVE DEFINED FIVE TRANSVERSAL FIELD OF ACTIONS (TFAs)



Cross Border Health: Enhancing equal access to highly specialized outcome-based healthcare and cross-border health for RHD in EU.



Telemedicine: Enabling the safe exchange of clinical information between healthcare professionals in order to provide expert advice about complex RHD cases through the Clinical Patient Management System (CPMS).



Best Practices: Promoting best practice in prevention, diagnosis and clinical care across EU by the development and update of ERN Clinical Practice Guidelines and other Clinical Decision Making tools.



Clinical trials & research: Strengthening the use and re-use of RHD health data through the European Rare Blood Disorders Platform (ENROL) for the provision of best healthcare and for the promotion of research and innovation.



Continuing Medical Education: Spreading cutting-edge knowledge and facilitate continuing medical education in the field of RHDs.

THE ERN-EUROBLOODNET THREE MAIN GOVERNING BODIES

ERN COORDINATION

Ensures the proper operational management of the network and the smooth functioning among the key players. Three main medical-scientific coordination centers make up the coordination team and ensure the deployment of the ERN strategic plan and the achievement of its objectives: Assistance Publique - Hôpitaux de Paris (AP-HP, ERN-EuroBloodNet coordinator), Université libre de Bruxelles (ULB/Hôp. Erasme HUB) and Vall d'Hebron University Hospital - Vall d'Hebron Research Institute (HUVH/VHIR).

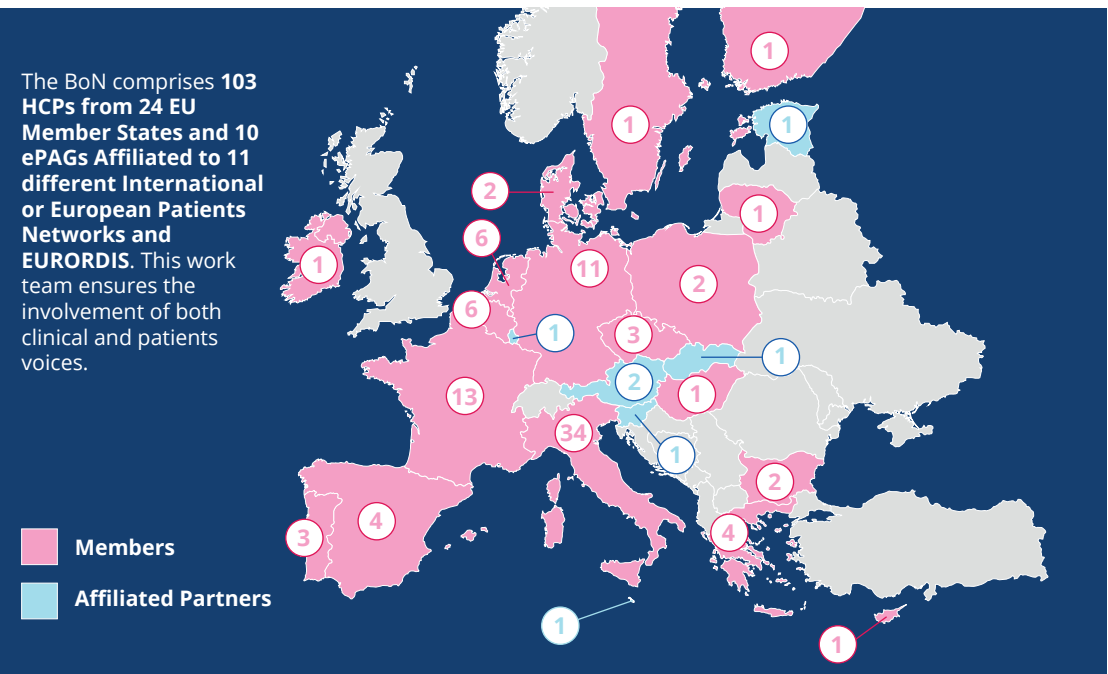
BOARD OF THE NETWORK (BoN)

The decision-making body, composed by all Members and Affiliated Partners representatives, and the ERN European Patients Advocacy Groups (ePAGs).

SCIENTIFIC AND STRATEGIC BOARD

Develops the multi-annual work plan, oversees ERN-EuroBloodNet actions, and assesses their impact. Composed by ERN Coordination, TFAs Coordinators, Subnetworks Coordinators and leaders of ongoing actions.

The BoN comprises **103 HCPs from 24 EU Member States and 10 ePAGs Affiliated to 11 different International or European Patients Networks and EURORDIS**. This work team ensures the involvement of both clinical and patients voices.



The ERN-EuroBloodNet Stakeholders Group (SG) assists the three governing bodies. SG includes:

- Supporting Partners (clinical or research)
- European Hematology Association (EHA)
- Other ERNs and Networks consortiums
- Orphanet
- EURORDIS