

THE ERN-EUROBLOODNET

Collaborative network that brings together individuals and institutions committed to **improving healthcare services in Rare Hematological Diseases.**

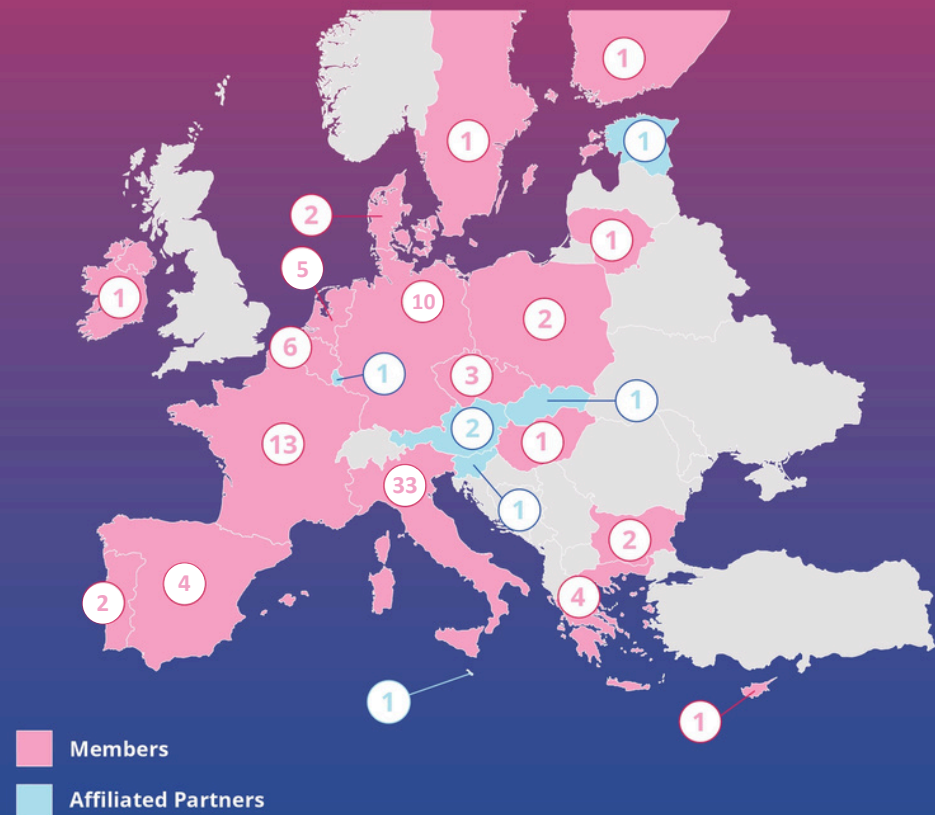
Oncological Hub

- Myeloid Malignancies
- Lymphoid Malignancies

Non-Oncological Hub

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

THE ERN-EUROBLOODNET MAP



11 EPAGs

7 Affiliated Partners in 6 Member States

90 Members in 18 Member States

THE MAIN HUBS OF ERN-EUROBLOODNET COORDINATION

Assistance Publique - Hôpitaux de Paris (AP-HP)
 Prof. Pierre Fenaux, ERN Coordinator, Chair of the oncological hub
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 Prof. Béatrice Gulbis, ERN co-Coordinator, Chair of the non-oncological hub
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Vall d'Hebron University Hospital - Vall d'Hebron Research Institute (HUVH/VHIR)
 Dr María del Mar Mañú-Pereira, ERN Scientific director and Coordinator of ENROL registry
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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!**



The European Reference Network on Rare Hematological Diseases

Five years promoting equal access for best health care in rare hematological diseases at the European level



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SINCE 2017, ERN-EUROBLOODNET IS WORKING TO IMPROVE THE HEALTHCARE SERVICES OF COMPLEX OR RARE HEMATOLOGICAL DISEASES (RHD) AND CONDITIONS THAT REQUIRE HIGHLY SPECIALIZED PROCEDURES IN EUROPE (EU).

TELEMEDICINE

CROSS BORDER HEALTH

To evaluate, at both the EU and Member State (MS) levels, the **adequate concentration of resources related to diagnosis, prevention and treatment in RHDs:**

- European repository of RHD experts and facilities from 96 members and 7 affiliated partners in 24 MS.
- 182 experts who can be found by disease (ORPHA code) or by subnetwork, age coverage, or expertise.
- 5 European mapping exercises conducted among ERN-EuroBloodNet members and non-members to establish the state-of-the-art on availability procedures at both the EU and MS levels:
 - I. Diagnosis of non-oncological disorders based on targeted new generation sequencing.
 - II. Diagnosis of Pyruvate Kinase Deficiency.
 - III. Diagnosis of Primary vitreo-retinal lymphoma.
 - IV. Transcranial Doppler to identify children with Sickle Cell Disease.
 - V. Bone marrow transplantation for non-oncological disorders.
- 22 RHD patients requesting Cross-Border health assistance have been supported by ERN-EuroBloodNet team by offering a mediation among National Contact Points for Cross Border Care and hospital administration.



Go to the ERN-EuroBloodNet repository of members and experts

BEST PRACTICES

Repository of Clinical practice guidelines (CPG) and other Clinical Decision-Making Tools (CDMTs):

- 69 RHD CPG and other CDMT adopted by the ERN and searchable by disease and quality domains.
- 3 new CDMTs:
 - I. Diagnosis and treatment of Metahemoglobinemia developed in collaboration with the European Hematology Association (EHA).
 - II. Newborn screening for Sickle Cell Disease – endorsed by the ERN.
 - III. Diagnosis of Pyruvate Kinase Deficiency – endorsed by the ERN.



Go to CPG and CDMTs



CONTINUING MEDICAL EDUCATION

Promotion of the development and spread of educational material/information in RHDs.

Educational actions for health professionals

- I. Webinar programs
 - a. Thursdays Webinars, 26 webinars (media of 28 participants) addressing cutting edge knowledge on clinical management or treatment.
 - b. Topic on Focus Webinars:
 - Cutaneous Lymphoma, 8 webinars (media of 78 participants), accredited with 7 European Board for Accreditation in Hematology (EBAH) credits.
 - Thrombotic Microangiopathies, 15 webinars (media of 41 participants), accredited with 11 EBAH credits.
- II. Anemias Training on Red blood cell morphology
- III. Preceptorships launched in 2022

Educational actions for patients

- I. 2 Patients Webinars (media of 43 participants) as webinars providing patients' community with highly specialized knowledge on a specific RHD or groups of disease.
- II. Topic on Focus for patients Webinars Program
 - Myelodysplastic syndromes, 7 webinars (media of 37 participants).
- III. Topic on Focus for Patients Organizations Webinars Program
 - Cutaneous lymphoma included 6 webinars (media of 41 participants).

All webinars available at ERN-EuroBloodNet EDU Youtube channel!



Go to Educational actions for health professionals



Go to Educational actions for patients

The Clinical Patients Management System (CPMS) aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of MS in EU:

- 80 experts registered
- 42 panels have been created, from which 21 are closed with outcome report produced.
- Development of the model "Virtual Boards on ultra-rare disorders" to promote the use of the CPMS. The first CPMS Virtual Board was established on Cutaneous Lymphoma:
 - I. 14 experts in 7 MS were trained on the use of the CPMS.
 - II. Organization of 13 Virtual Board video meetings.
 - III. 9 cases enrolled in the CPMS with 8 outcome reports generated.



Go to telemedicine CPMS

CLINICAL TRIALS AND RESEARCH

The ERN-EuroBloodNet Research agenda include three main pillars:

- **Research Pillar 1: Epidemiological surveillance and re-use of data**
 - I. ENROL Registry designed to avoid fragmentation of data by promoting the standards for patient registries' interoperability released by the EU RD platform. 4 concrete RHD areas with ongoing collaboration:
 - Blastic plasmacytoid dendritic cell neoplasm: EU-BLAST
 - Myelodysplastic Syndromes
 - Rare Anemia Disorders: RADeep
 - Bleeding and coagulation disorders: von Willebrand Disease: TWIST
 - II. Collaborative Platform on red blood cells diseases and COVID-19 patients, a EU registry platform to pool information aiming to quickly identify the impact of COVID-19 on patients with red blood cell disorders and to enable inter-professional consultations.



42 medical centers from 10 EU countries have registered 373 patients.

Research Pillar 2: Collaborative Translational Research projects

Promoting the establishment of collaborative research projects among ERN-EuroBloodNet members.



Research Pillar 3: Promotion of clinical trials (CT) in RH

The analysis of the state of the art on rare hemolytic anemias (RHAs) clinical trials showed that only 25% RHAs were covered by at least one CT. Only 19% of the CTs were open in Europe and from this, 50% were active in ERN-EuroBloodNet members from 5 member states.



Go to research