

ERN-EuroBloodNet

The European Reference Network on Rare Hematological Diseases



**Removing
barriers**

*for making highly
specialized services
available to
everyone*



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)

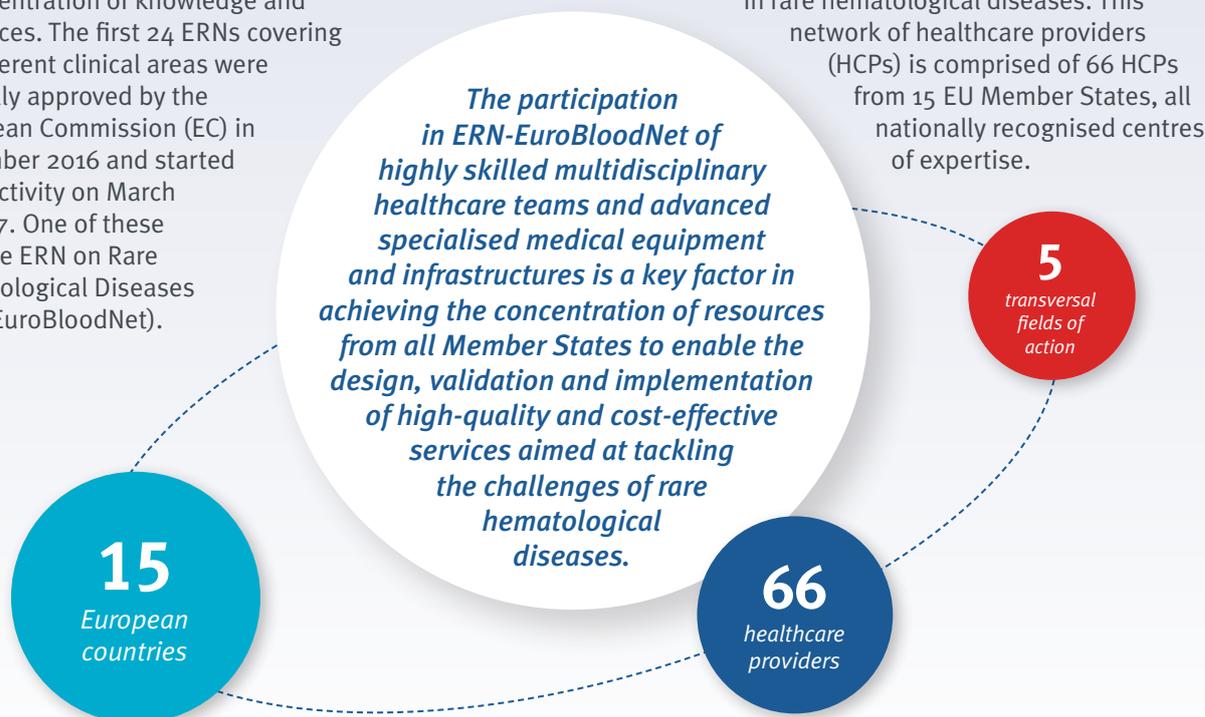
Who we are

Due to the small number of patients and the often limited knowledge, rare diseases, affecting less than 1 in 2000 individuals, are the area in public health in which joint efforts among European Member States is most justified and crucial.

Directive 2011/24/EU on patients' rights in cross-border healthcare establishes the creation of European Reference Networks (ERNs) based on national recognized Centres of Expertise, aiming to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. The first 24 ERNs covering 24 different clinical areas were officially approved by the European Commission (EC) in December 2016 and started their activity on March 1st 2017. One of these was the ERN on Rare Hematological Diseases (ERN-EuroBloodNet).

ERN-EuroBloodNet results from a joint effort of the European Hematology Association (EHA, www.ehaweb.org), the European Network on Rare and Congenital Anaemias (ENERCA, www.enerca.org), and the European hematology patient organisations represented in both the EURORDIS European Patient Advocacy Groups - ePAGs (www.eurordis.org) and the EHA Patient Organisations Workgroup.

ERN-EuroBloodNet is a collaborative network that brings together individuals and institutions committed to improving healthcare services in rare hematological diseases. This network of healthcare providers (HCPs) is comprised of 66 HCPs from 15 EU Member States, all nationally recognised centres of expertise.



Subnetworks

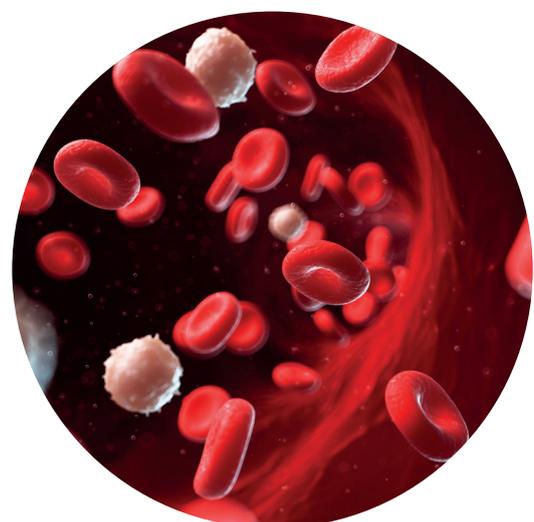
ERN-EuroBloodNet ensures the coverage of rare hematological diseases through their inclusion in two main hubs: the oncological diseases hub (including two subnetworks for the coverage of adult patients) and the non-oncological diseases hub (including four subnetworks for the coverage of paediatric and adult patients). Each subnetwork is coordinated by two physicians and one ePAG's representative.

Oncological diseases hub

- Myeloid malignancies
- Lymphoid malignancies

Non-oncological diseases 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



Main goals and transversal fields of action

Our main goal is to promote excellence for best healthcare in rare hematological diseases (RHD) based on cutting-edge diagnosis procedures and therapies while removing barriers for making them available at the European level.

In line with this goal, the following five specific objectives have been identified and linked to specialized Transversal Fields of Action (TFA) for the establishment and implementation of the annual work plan:



Independent Advisory Board

Barbara de la Salle	UK NEQAS General Haematology
Didi Jasmin	European School of Haematology
Amanda Neville	European Surveillance of congenital anomalies
Pilar Nicolás	Chair in Law and the Human Genome - University of the Basque Country
Carin Smand	European Hematology Association
Joan Lluís Vives Corrons	ENERCA coordinator / University of Barcelona - Josep Carreras Leukaemia Research Institute

The governance and coordination of ERN- EuroBloodNet will be continuously supported by the activities of two functional structures:

- Board of the Network (BoN)
- Scientific and Strategic Board (SSB)

In addition, an Independent Advisory Board has been established for seeking advice on specific issues.

ERN-EuroBloodNet Ongoing Projects

During ERN-EuroBloodNet second year of implementation a new strategical structure was defined in order to promote the direct participation of members on the different ongoing actions launched by the network while facilitating their coordination and monitoring.

In this context, a list of concrete ongoing projects was launched focused on the different Transversal Fields of Action and Rare Hematological Diseases areas where members are actively involved. This list is in continuous evolution and expansion since all members are welcomed to suggest and launch new concrete projects under the umbrella of the network. **Visit <http://www.eurobloodnet.eu> to keep updated on the ongoing projects and how to be involved!**

Each project has several active coordinators that are in charge of the specific actions to be undertaken under concrete ongoing project. **If you are willing to launch and/or coordinate a new project do not hesitate to contact us!**



Scientific and Strategic Board (SSB)

The Scientific and Strategic Board (SSB) is composed by the coordination team members, the coordinators of the six subnetworks and the coordinators of the five transversal fields of action.

The main functions of the SSB are to:

- Define the multi-annual work plan (MWP) to ensure the achievement of ERN-EuroBloodNet objectives.
- Execute the BoN decisions and the operational implementation of the MWP.
- Assess the level of impact of outcomes.
- Ensure the outreach of results at the European and Member States levels.

Board of the Network (BoN)

The Board of the Network (BoN) is the decision-making body. It is chaired by the ERN coordinator and composed by the coordination team, all member representatives and ePAGs' representatives.

The main functions of the BoN are to:

- Guarantee the smooth running of ERN-EuroBloodNet, oversee development of services and assess their impact.
- Adopt the legal framework for collaboration with third parties, as European infrastructures for research, industries...
- Develop funding strategies for long-term sustainability.
- Elect the heads of subnetworks and the heads of the transversal fields of action, and approve the multi-annual work plan developed by the Scientific and Strategic Board (SSB).

ePAGs' representatives

ePAG Hematology

Pierre Aumont	Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström
Amanda Bok	European Haemophilia Consortium (EHC)
Loris Brunetta	Thalassaemia International Federation / Associazione Ligure Talassemici Onlus
Jan Geissler	Leukemia Patient Advocates Foundation
Maria Piggin	Paroxysmal nocturnal hemoglobinuria (PNH) support
Ananda Plate	Myeloma Patients Europe (MPE)
Dag Erling Stakvik	European Federation of Associations of Patients with Haemochromatosis (EFAPH)
Sophie Wintrich	MDS UK Patient Support Group (and MDS Alliance)

Patients advocacy

Patients are important actors of ERNs. The involvement of patients' organizations in the Board of ERN-EuroBloodNet has been ascertained from the onset in order to guarantee their pivotal role within the network and keep ERN-EuroBloodNet's patient-centred-approach.

EURORDIS – Rare Diseases Europe (www.eurordis.org) has played an active advocacy role over the last ten years for the emergence of ERNs. It has established European Patient Advocacy Groups – ePAGs – for each ERN and is ensuring a transversal coordination as well as providing specific training programmes.

Eight ePAGs' representatives are currently ensuring full patient representation in ERN-EuroBloodNet board and SSB. More ePAGs' representatives are joining as the network is growing.

Members

Country	Healthcare provider name	Representative	Substitute representative
FR	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis	Régis Peffault de Latour	Pierre Fenaux
BE	CUB-Hôpital Erasme	Béatrice Gulbis	Florence Roufosse
BE	Jules Bordet Institute	Dominique Bron	Sebastian Wittnebel
BE	University Hospital Leuven	Kathelijne Peerlinck	Chris Van Geet
BE	University Hospital Liège	Yves Beguin	Frédéric Baron
BE	University Hospitals Saint-Luc	Cedric Hermans	Catherine Lambert
BG	Varna Expert Center of coagulopathies and rare anemias	Valeriya Kaleva	Elina Peteva
BG	Expert Center on coagulopathias and Congenital Anemias	Toshko Lissitchkov	Stanislav Simeonov
CY	Archbishop Makarios III Hospital	Soteroula Christou	Evdokia Pangalou
CZ	University Hospital Brno	Jiri Mayer	Michael Doubek
DE	Universitätsklinikum Carl Gustav Carus	Martin Bornhaeuser	Friedrich Stölzel
DE	Universitätsklinikum Heidelberg	Stefan Schönland	Ute Hegenbart
DE	Charité Universitätsmedizin Berlin	Lena Oevermann	Dani Hakimeh
DE	Universitätsklinikum Köln	Michael Hallek	Andreas Engert
ES	Hospital Universitari Vall d'Hebron	Cristina Diaz de Heredia	David Beneitez
FR	CHU de Montpellier	Patricia Aguilar-Martinez	Jean-François Schved
FR	CHU de Limoges	Arnaud Jaccard	Frank Bridoux
FR	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Antoine	Paul Coppo	Eric Rondeau
FR	Institut Curie	Carole Soussain	Sandra Malak
FR	Assistance Publique-Hôpitaux de Marseille	Isabelle Thuret	Herve Chambost
FR	CHU de Rennes	Edouard Bardou-Jacquet	Houda Hamdi-Roze
FR	CHRU de Lille	Jenny Goudemand	Louis Terriou
FR	CHU de Pointe-à-Pitre/Abymes	Maryse Etienne-Julan	Marie Petras
FR	Assistance Publique-Hôpitaux de Paris, Hôpital Trousseau	Jean Donadieu	Abdellatif Tazi
FR	Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor	Frédéric Galacteros	Pablo Bartolucci
FR	Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades	Olivier Hermine	Mariane de Montalembert
IE	Our Lady's Children Hospital Crumlin	Corrina McMahon	Emma Tuohy
IT	Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic - Milan	Maria Domenica Cappellini	Flora Peyvandi
IT	AOU Federico II - Naples	Achille Iolascon	Antonio Risitano
IT	Foundation IRCCS Polyclinic San Matteo, Pavia	Luca Malcovati	Giovanni Palladini
IT	S. Gerardo Hospital - Monza	Alberto Piperno	Nicoletta Masera
IT	AO Padua	Alessandra Biffi	Raffaella Colombatti
IT	San Bortolo Hospital - Vicenza	Alberto Tosetto	Marco Ruggeri
IT	Hospital Pope John XXIII - Bergamo	Anna Falanga	Luca Barcellona
IT	AOU Careggi, Florence	Giancarlo Castaman	Alessandro Vannucchi
IT	AOUI Verona	Domenico Girelli	Lucia De Franceschi
IT	Foundation CNR Tuscany Region G. Monasterio	Pepe Alessia	Claudio Favre
IT	AOU Second University - Naples (SUN)	Silverio Perrotta	Maddalena Casale
IT	E.O. Ospedali Galliera, Genoa	Gian Luca Forni	Valeria Pinto
IT	IRCCS Institute Giannina Gaslini - Genoa	Carlo Dufour	Maurizio Miano
IT	AOU S. Luigi Gonzaga	Antonio Piga	Filomena Longo
IT	AOU Policlinico Umberto I - Rome	Roberto Foà	Fiorina Giona
IT	AOU Siena	Monica Bocchia	Alessandra Renieri
IT	Riuniti hospitals Villa Sofia-Cervello - Palermo	Aurelio Maggio	Lorella Pitrolo
IT	AOU Modena	Antonello Pietrangelo	Lorenzo Iughetti
IT	IRCCS Clinical Institute Humanitas - Rozzano	Matteo Giovanni Della Porta	Marianna Rossi
IT	AOU Consorziata polyclinic - Bari	Paola Giordano	Giovanni Carlo Del Vecchio
IT	Foundation Polyclinic University A. Gemelli - Rome	Andrea Bacigalupo	Valerio de Stefano
LT	Vilnius University Hospital Santariškių Klinikos	Laimonas Griskevicius	Sonata Saulyte
NL	University Medical Center Groningen	Karina Meijer	Rienk Tamminga
NL	Academic Medical Center Amsterdam	Karin Fijn van Draat	Bart Biemond
NL	University Medical Center Utrecht	Roger Schutgens	Eduard van Beers
NL	Erasmus MC: University Medical Center Rotterdam	Pieter Sonneveld	Marjon Cnossen
NL	Radboud University Medical Center Nijmegen	Dorine Swinkels	Nicole Blijlevens
NL	Leiden University Medical Center	Felix van der Meer	Arjan Lankester
PL	Maria Skłodowska Curie Memorial Institute of Oncology	Jan Walewski	Anna Dabrowska-Iwanicka
PT	Instituto Português de Oncologia do Porto Francisco Gentil, EPE	José Mario Mariz	Luísa Viterbo
PT	Centro Hospitalar do Porto, EPE	Graça Porto	Margarida Lima
PT	Centro Hospitalar e Universitário de Coimbra, EPE	Maria Letícia Ribeiro	Tabita Magalhaes Maia
SE	Karolinska University Hospital	Mikael Sundin	Eva Hellström-Lindberg
UK	Sheffield Teaching Hospitals NHS Foundation Trust	Michael Makris	Catherine Harrison
UK	Imperial College Healthcare NHS Trust	Jane Apperley	Michael Laffan
UK	Oxford University Hospitals NHS Foundation Trust	Andy Peniket	Noemi Roy
UK	Guy's and St Thomas' NHS Foundation Trust	Baba Inusa	Jo Howard
UK	University College London Hospitals NHS Foundation Trust	Shirley D'Sa	Marie Scully
UK	Barts Health NHS Trust	Paul Telfer	Banu Kaya



Contact us:

Prof Pierre Fenaux
Coordinator
 Oncological Hub Chair
 pierre.fenaux@aphp.fr

Prof Béatrice Gulbis
Co-coordinator
 Non-oncological Hub Chair
 Beatrice.Gulbis@erasme.ulb.ac.be

Dr María del Mar Mañú Pereira
Scientific Director
 mar.manu@vhir.org

Victoria Gutiérrez Valle
IT and Dissemination Manager
 victoria.gutierrez@vhir.org

Mariangela Pellegrini
ERN Manager
 mariangela.pellegrini@aphp.fr

Fahed Ahssini
CPMS Operational Helpdesk
 Fahed.Ahssini@erasme.ulb.ac.be



The content of this leaflet represents the views of the author only and it is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for any use that may be made of the information it contains.