ERN-EuroBloodNet

The European Reference Network on Rare Hematological Diseases



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 crossborder 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

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.

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.

The participation
in ERN-EuroBloodNet of
highly skilled multidisciplinary
healthcare teams and advanced
specialised medical equipment
and infrastructures is a key factor in
achieving the concentration of resources
from all Member States to enable the
design, validation and implementation
of high-quality and cost-effective
services aimed at tackling
the challenges of rare
hematological
diseases.

transversal fields of action

15 European countries

66
healthcare
providers

Subnetworks

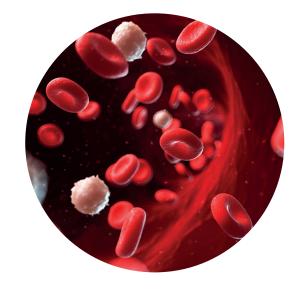
ERN-EuroBloodNet ensures the coverage of rare hematological diseases through their inclusion in two main hubs: the oncological diseases hub (including two subnetworks for the coverage of adult patients) and the non-oncological diseases hub (including four subnetworks for the coverage of paediatric and 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:

TFA on Cross-border health aims to establish a referral system for patients TFA on Clinical trials and and samples in order to ensure the same research aims to foster European level of access to healthcare across cooperation for epidemiological Europe in accordance with the Directive surveillance, promote the access 2011/24/EU on patients' rights in crossto clinical trials, facilitate the border healthcare. provision of new technologies and the establishment of Cross-border health collaborative research projects in the field of RHD. **Clinical trials Equal access** and research Improve equal access to highly specialized healthcare delivery for **RHD** across Europe **Innovative** therapies **Best practices** Foster European Promote best practices in cooperation in highly prevention, diagnosis and specialized procedures for safe clinical care across diagnosis, innovative Europe **EuroBloodNet** treatments and research Inter-

Telemedicine

TFA on Telemedicine aims to facilitate consultation of RHD complex cases for diagnosis or clinical care by connecting health professionals in distant locations while contributing to the future development of the telemedicine tool created by the EC: the Clinical Patients Management System.

Interprofessional consultation

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

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

3 Continuing

Continuing medical education

TFA on Continuing medical education aims to spread cutting-edge knowledge by the implementation of a blended educational program (on-site & on-line) with innovative contents and directed by the most outstanding experts in RHD.

Best practices

TFA on Best practices aims to compile, foster the creation and assess the implementation of guidelines in RHD, alongside their dissemination across Europe.

Each TFA is led by one oncological hub coordinator, one non-oncological hub coordinator and one ePAG's representative coordinator.

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!

Prof Béatrice Gulbis

Co-coordinator

Non-oncological Hub Chair CUB-Hôpital ERASME, Brussels LHUB-ULB

Prof Pierre Fenaux

Coordinator

Oncological Hub Chair Hôpital Saint-Louis, Paris

Coordination team

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Hôpital Saint-Louis, Paris

Fahed Ahssini

CPMS Operational Helpdesk

CUB-Hôpital ERASME, Brussels LHUB-ULB

Dr María del Mar Mañú Pereira

Scientific Director

University Hospital Vall d'Hebron - Vall d'Hebron Research Institute, Barcelona

Victoria Gutiérrez Valle IT and Dissemination Manager

University Hospital Vall d'Hebron - Vall d'Hebron Research Institute, Barcelona

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 infraestructures 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 multiannual 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

Thalassemici 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

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