#### Contact us:

**Prof Pierre Fenaux**Coordinator

Oncological Hub Chair pierre.fenaux@aphp.fr

Prof Béatrice Gulbis ERN Manager
Co-coordinator mariangela.pel
Non-oncological Hub Chair
Beatrice.Gulbis@erasme.ulb.ac.be Fahed Ahssini

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

www.eurobloodnet.eu
Follow us on Twitter @ERNEuroBloodNet















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.

# **ERN-EuroBloodNet**

The European Reference Network on Rare Hematological Diseases





for rare or low prevalence complex diseases

Network
 Hematological
 Diseases (ERN EuroBloodNet)

Hope for patients with rare hematological diseases

## What do we offer?

- 66 highly skilled and multidisciplinary healthcare teams in 15 Member States
- Advanced specialized medical equipment and infrastructures
- Concentration of resources for the design, validation and implementation of high-quality and cost-effective services
- Patient-centred approach

#### Bringing together patients and health professionals to better shape clinical care.

### **Patients**

The involvement of patients organizations in the Board of ERN-EuroBloodNet has been ascertained from the outset in order to guarantee their pivotal role within the network.

EURORDIS – Rare Diseases Europe (www.eurordis.org) has established European Patient Advocacy Groups – ePAGs – for each ERN and is ensuring transversal coordination as well as providing specific training programmes.

Eight ePAGs' representatives are currently ensuring that the patient's voice is fully represented in the ERN-EuroBloodNet Board and increasing the role of patients in clinical care in Europe. More ePAGs are joining as the network is developing!

Stay updated at www.eurobloodnet.eu

If you have a rare hematological disease, you are not alone.

Contact us to see how we can help you.

If you are visiting
a patient with a rare
hematological treating,
you are not working alone.
Contact us to see how
we can help you.

### **Professionals**

ERN-EuroBloodNet professionals work together to:

- Establish a European cross-border referral system for patients and samples.
- Promote evidence-based guidelines by pooling expertise within the network.
- Disseminate cutting-edge knowledge and facilitate continuing medical education.
  - Provide inter-professional consultation by sharing of expertise and the safe exchange of clinical information.
    - Gather the critical mass needed for the development of innovative therapies, clinical trials and cuttingedge methodologies for diagnosis.

ERN-EuroBloodNet seeks to guarantee that European citizens affected by rare hematological diseases can benefit from the same level of highly specialised care, thereby improving their overall quality of life, and reducing inequalities across Europe for access to healthcare.

ERN-EuroBloodNet encompasses oncological (for adult patients) and non-oncological (for adult and paediatric patients) rare hematological diseases including myeloid and lymphoid malignancies, rare anemias, bone marrow failure disorders, rare bleeding-coagulation disorders and rare hereditary hemochromatosis.