



ERN-EuroBloodNet actions on oncological diseases

Aims

- ❖ Coverage (> 450 rare, complex diseases)
- ❖ Not to duplicate, but to find gaps and improve what is in place
- ❖ Patients' centered

ERN-EuroBloodNet 6 disease areas

2 oncological disease areas (adults):

- ❖ Lymphoid malignancies
- ❖ Myeloid malignancies

4 non-oncological disease areas (pediatrics and adults):

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

ERN-EuroBloodNet Members & patients involvement

- ❖ 97 HCPs in 24 EU Member States
 - ❖ 44 HCPs covering Lymphoid malignancies
 - ❖ 46 HCPs covering Myoid malignancies
- ❖ 11 ePAGs (ERNs patients advocacy groups)
 - ❖ 5 ePAGs on oncological diseases
- ❖ 52 National Patients Organizations involved in ERN
 - ❖ 11 on oncological diseases



Cross Border Health

- ✓ Repository of experts and Highly Specialized Procedures at website
- ✓ 19 Oncological patient requests for cross-border health assistance



Best Practices

- ✓ 26 oncological Guidelines endorsed by ERN-EuroBloodNet. Repository searchable in website.
- ✓ 2 oncological Guidelines written by the ERN: Burkitt lymphoma, Vexas syndrome
- ✓ EU Mapping on diagnosis of Primary vitreoretinal lymphoma
- ✓ EU Mapping on access to Myeloproliferative neoplasm treatments



Education

- ✓ 109 Accredited & Non Accredited educational actions (Webinars, Videos, Trainings) on oncological diseases for Health Professionals & Patients
- ✓ 2 Preceptorship programs on oncological disorders



CPMS

- ✓ 20 oncological cases discussed for cross border advice



Clinical Trials

- ✓ Sponsoring academic CT



ENROL Registry

- ✓ ERN-EuroBloodNet registry for all Rare Hematological Diseases
- ✓ Collaboration to establish EU Registry on Blastic plasmacytoid dendritic cell neoplasm
- ✓ Collaborations for Artificial Intelligence and data driven solutions:
 - ✓ GenoMed4All – Use case Myelodysplastic syndromes
 - ✓ SYNTHEMA – Use case Acute myeloid leukaemia
 - ✓ IMPACT –AML – for R/R Acute myeloid leukaemia

