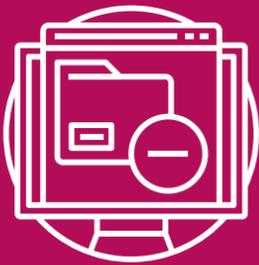


WORLD SICKLE CELL Awareness Day 2023

COVERING MORE THAN 400 RARE AND COMPLEX HEMATOLOGICAL DISEASES, ERN-EUROBLOODNET OFFERS ITS ONLINE FACILITIES, SERVICES AND EXPERTISE TO SUPPORT ORPHAN BLOOD DISORDERS

ERN-EuroBloodNet's multi level actions on SCD aims at wide distribution of knowledge & cross border patients support

1 EUROPEAN PATIENTS REGISTRIES



- [ENROL](#) - European Rare Blood Disorders Platform
- [RADeep](#) - The Rare Anemia Disorders European Platform
- [Collaborative Platform on RBCDs and COVID-19 patients](#)

2 RESEARCH

- [GenoMed4All](#) - Genomics and Personalized Medicine for all through Artificial Intelligence in Haematological Diseases
- [EVIDENCE](#) - Erythrocytes Properties and Viability in Dependence of Flow and Extra Cellular Environment
- [INHERENT](#) - International Hemoglobinopathy Research Network
- [EDITSCD](#) - Assessing efficacy and safety of genome EDITing approaches for SCD
- [SYNTHEMA](#) - Synthetic generation of HEMAtological data over federated computing frameworks

3 CONTINUING MEDICAL EDUCATION

- [Webinars](#)
- [Preceptorships](#)
- [Training Course on Transcranial Doppler](#)



4 PATIENTS EMPOWEREMENT

- [Webinars](#)
- [Annual SCD Patients Sessions](#) at the international “Annual Sickle and Thalassemia” Scientific Congress (ASCAT).
- [Facilitating the launching](#) of a patient driven bottom up European Network of SCD Patients Organization
- Patients Storytelling ([Blog](#), [Testimonies Videos](#), [Articles&Posters](#))
- Assessing Patients Needs (Survey, [National & European Meetings](#)).
- [Cross Border Health Assistance](#)
- [Patients Conversations Group with psychotherapist](#)

5 BEST PRACTICE



- [Repository](#) of Reference Center for SCD in Europe
- [Repository](#) of SCD CPGs and other CDMTs & analysis of discrepancies
- [Endorsement of recommendation](#) for SCD Newborn Screening
- [Mapping of highly specialized procedure](#) in Europe aiming to evaluate the availability of Transcranial Doppler for children with SCD
- Cross border health agreement between European Member States: bone marrow transplant between Italy and Ireland



Co-funded by the European Union

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.

www.eurobloodnet.eu
coordination@eurobloodnet.eu
www.eurobloodnet.eu/newsletter/