

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 EMPOWERMENT

- [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



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