

ERN-EuroBloodNet: facilitating the establishment of a Patient-Driven European Network of SCD Patient Organisations

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Sickle Cell Disease (SCD) is an inherited disorder of the red blood cells, traditionally endemic in African and Middle East countries. A lifelong chronic condition that can lead to disability or premature death in its severe forms.

SCD frequency has increased recently in Europe due to migration and mobility flows.

Patients' organizations (POs) presence at the national level is extremely varied from country to country. Many countries in Europe have no patients organization.

How to?



1. Identify SCD POs in Europe
2. Invite POs to National Meetings
3. Encourage, if not existing yet, to form a national association/federation/group
4. Election of national representatives
5. Establishment of the board in kick off meeting
6. Organization of Educational sessions for empowerment of patients advocates

+50
Patients
organisations
reached

National Meetings



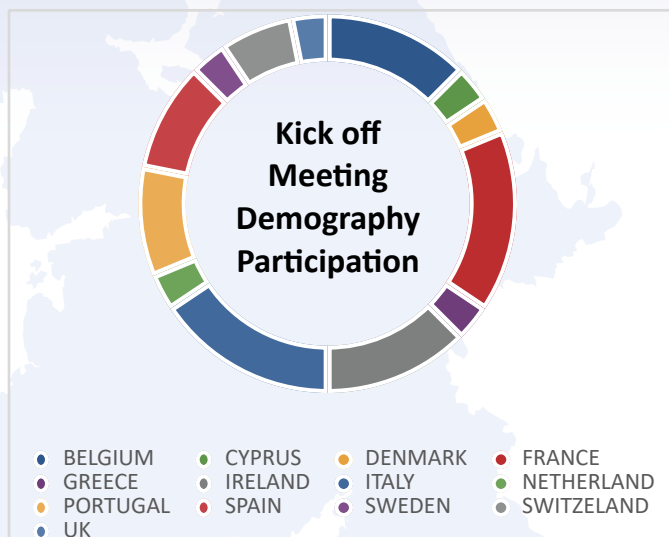
- Milan, the 29th of March 2019
- Brussels, the 19th of June 2019 Informative Meeting
- Paris, the 29th of June 2019
- Madrid, gathering Spanish and Portuguese patients, 18th February 2020

The European Reference Network on rare hematological diseases, ERN-EuroBloodNet, in collaboration with EURORDIS, is facilitating the creation of an European Network of Sickle Cell Disease (SCD) Patients Organizations

Characteristics



- A **bottom-up umbrella** network of national and local organizations of SCD patients' advocates
- Each Country is represented by **2 spokesmen** on behalf of all the national patients' organizations.
- Among all spokesmen a representative one would become **ePAG** for the ERN-EuroBloodNet.



Kick off Meeting, 20th December 2021

- Evaluation of the maturity of the plan of facilitating the creation of a bottom-up European Network of SCD Patients Organizations
- Identification of first potential actions carried by the Patients' Organisations Group
- Identification of first potential SCD patients candidates for becoming ePAGs.

National patients' representatives identified for Italy, France, Spain, Portugal and Belgium