

# ERN-EuroBloodNet: Establishment of the European Network of Sickle Cell Disease Patients Organizations

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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 (ASCAT 2019 and 2020, UNESCO 2020)

12  
European  
countries  
reached

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

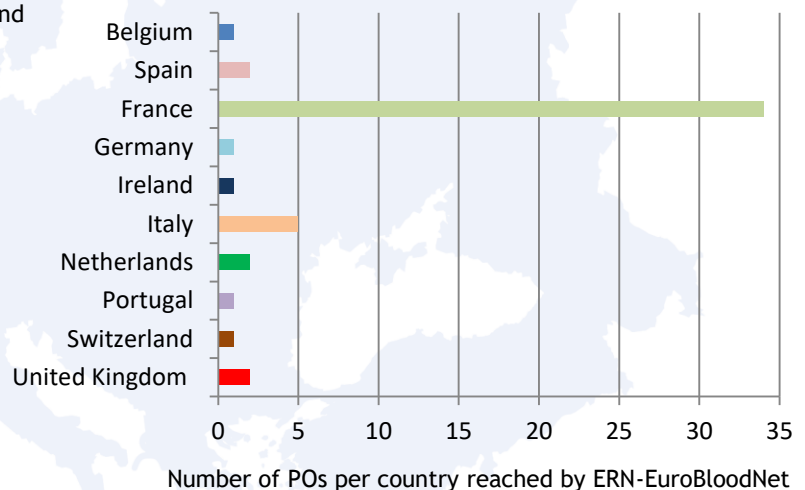
## Characteristics



- 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.

50  
Patients  
organisations  
reached

## Patients Organizations 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

*A common unique voice for SCD patients advocates in Europe*