

PATIENT THERAPEUTIC EDUCATIONAL SESSION AT INTERNATIONAL CONGRESS. THE MODEL OF ERN-EUROBLOODNET AT ASCAT



Mariangela Pellegrini¹, Subarna Chakravorty², Maria del Mar Manu Pereira³, Beatrice Gulbis⁴, Catriona Gilmour-Hamilton⁵, Sandy Hayes⁵, Mariane de Montalembert⁶, Baba Inusa⁸, Raffaella Colombatti*⁹ & Noémi Roy*⁵ (*equal contribution)

¹Assistance Publique – Hôpitaux de Paris, Hôpital Saint Louis, Member of European Reference Network on Rare Hematological Diseases

²King's college Hospital NHS Foundation Trust

³Vall d'Hebron Research Institute/Vall d'Hebron University Hospital, Member of European Reference Network on Rare Hematological Diseases

⁴Hôpital Erasme/LHUB-ULB, Member of European Reference Network on Rare Hematological Diseases

⁵Oxford University Hospitals

⁶Assistance Publique – Hôpitaux de Paris, Hôpital Necker, Member of European Reference Network on Rare Hematological Diseases

⁸Guy's and St Thomas' NHS Foundation Trust

THE EXPERIENCE WITH SICKLE CELL DISEASE PATIENTS

2019-2021

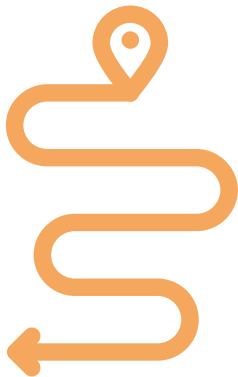
Sickle Cell Disease (SCD) is a lifelong inherited red blood cell disorder which can lead to disability or even premature death in its severe forms. People living with SCD in Europe mainly belong to social minorities and are more isolated, have a lower level of health education and poorer adherence and disease management compared with patients with other hematologic diseases.

Aiming to promote patient-centered research in SCD and engage people living with the condition in this process, we set out to develop patient centered actions in the frame of international scientific conferences :



- **Creating a group of people living with SCD to let them expressing their needs and share experience and best practices**
- **Training patients in Patient Therapeutic Education (PTE) and Public Patient Involvement in Research**
- **Evaluating in Europe the impacts of PTE session on patients and their families**
- **Creating further connections among healthcare professionals and patients**
- **Making visible to scientific community patients' needs and expectations**

ROADMAP



- Identify a group of patients in Europe
- Organise a Patient Therapeutic Education or Public Patient Involvement Session at International Scientific Congress
- Present the outcomes of the Patients Session at the Closing Plenary of the International Scientific Congress

SCD Research Prioritisation Workshop



ASCAT 2019

- 33 participants
- 8 EU countries, 5 non-EU countries
- 28 Patients and parents
- 10 Patient associations
- 7 Healthcare professionals
- > SCD Top 10 priorities research topics presented at the Closing Plenary

SCD PTE Online Session



ASCAT 2020

- 70 registered participants
- 9 EU Countries, 5 non-EU countries
- 48 Patients and parents
- 31 Patient associations
- 22 Healthcare professionals
- > Outcomes presented at the Closing Plenary

SCD PTE Online Sessions



ASCAT 2021

- 54 registered participants
- 6 EU Countries, 5 non-EU countries
- 48 Patients and parents
- 14 Patient associations
- 8 Healthcare professionals
- + 363 attendees connecting from ASCAT Congress Platform
- > Outcomes presented at the Closing Plenary

In collaboration with ERN-EuroBloodNet, Oxford Blood Group, Annual Sickle Cell Disease and Thalassemia Conference (ASCAT), the European Hematology Association and the British Society of Hematology