

AGENDA

SCD PATIENTS' EDUCATIONAL SESSION ASCAT 2020 (26th – 31st October)

26th of October 2020

5 pm- 7.40 pm (PARIS CET Time)

1. (5pm - 5.10 pm) Welcome&Opening

Moderated by Raffaella Colombatti, Mariangela Pellegrini and Agnes Nsofwa

- a. Recap on last year's meeting including ASCAT video produced by EuroBloodNet containing participants' testimonies and workshop results.

2. (5.10 pm – 6.30 pm) Webinar

Moderated by Noemi Roy and Funmi Dasaolu

- a. **(5.10 pm – 5.20 pm) Pre-recorded session** with the COVID patients experience from London
→ 3 patients testimonies from London :

Reia Costa (UK)

Ayodele Ibidapo-Obe (UK)

- b. **(5.20 pm – 5.30 pm) Pre-recorded session** with EuroBloodNet representatives about how patients with SCD coped during the lockdown, access to treatment, services, follow up
→ 3 patients testimonies from Europe

Andreas Athanasiou (CY)

Diabana BA (FR)

Decio Temporario (PT)

- c. **(5.30 pm - 5.40 pm) Live Session Voluntary/Third sector**

Discussion on the role of Voluntary/Third sector during the pandemic (10 minutes).

→ **1 SCD patients representative testimonies**

N' Zallah B. Zamani (Nigeria)

(5.40 pm- 5.50 pm) 10 min break

- d. **(5.50 pm – 6.30 pm) Debate** (Summary of key messages + questions raised during testimonies + moderators gather questions written in the chat)

3. (6.30 pm – 6.45 pm) Peer reviewing experience in UK

Moderated by Noemi Roy and Sharon Brown-Peters

- a. **Pre-recorded session** by a patient who would like to share their experience (5 min).
→ **2 SCD patients representative testimonies**

Vanessa Wills (UK)

June Okochi (UK)

- b. **Q&A session.** (Summary of key messages +pre-identify questions raised by testimonies +some questions in the chat) (10 min).

(6.45 pm – 6.55 pm) 10 min break

4. (6.55 pm - 7.25 pm) Why I took part in research)

Moderated by Noemi Roy and Miriam Santos

- a. **Pre-recorded session** by a patient who would like to share their experience
→ **3 SCD patients testimonies**

Kuseke Sona Luce (FR)

Miriam Santos (Portugal)

Oluyemi Moses (USA)

- b. **(7.25 pm – 7.40 pm)Q&A Session** (Summary+ Q&A pre-identify questions raised by testimonies +some questions in the chat). (15 min)

28th of October 2020

5 pm – 7.40 pm (PARIS CET Time)

5. (5pm – 5.50 pm) “Meet the expert” session with live Q&A
Moderated by: Raffaella Colombatti, Subarna Chakravorty, Esther Owuta Pepple Onolememen

Panel of physicians: 2 paediatricians, 2 adults haematologist

- a. **Topics identified with a survey submitted to SCD patients**
- Newborn and infant SCD Screening, **Stephan Lobitz, Germany**
 - Neurological Complications in SCD, **Maddalena Casale, Italy**
 - Adult Patients Quality of Life, **Jeremy Anderson, UK**
 - BMT: survival infertility and other complications, **Jean-Hugues Dalle, France**
 - New therapies for SCD, **John Brewin, UK**

(5.50 m – 6 pm) 10 min break

6. (6 pm – 6.50 pm) “Meet the patient” 2 parallel sessions with live Q&A

1st Parallel session “Meet the patient”: Physicians addressing questions to adult patients

Moderated by: Subarna Chakravorty and Biba Tinga

Panel of Patients:

Ibidapo-Obe (UK)

Kuseke Sona Luce (FR)

Cassandra Timnel (USA)

2nd Parallel session “Meet the patient”: Teenagers patients addressing questions to adult patients

Moderated by: Raffaella Colombatti and Wilhermina Naa Koshie Lamptey

Panel of Patients:

Awa Kekeh (FR)

Marsha Mothersill (UK)

Michele Nkoudou (IT)

(6.50 pm - 7 pm) 10 min break

7. (7 pm – 7.40 pm) 'My life, my word'

Moderated by: Mariane de Montalembert and Sola Njoku

- a. **Pre-recorded session:** paediatric or young patients express their view/questions about their life with SCD.
Devard Jones (UK)
Kaltouma MAHAMAT NOUR (FR)
Judy Grandison (Canada)
Gutam Dongre (India)
- b. **Q&A session** (pre-identify questions raised by testimonies +some questions in the chat 15 min)

31st of October 2020

Moderated by: Beverley Francis-Gibson and Anie Kofi

- 8. **(2 pm- 3.15 PARIS CET time pm) Q&A session** (Question raised in previously sessions but not enough addressed + new questions and comments) (1h)
- 9. **Plenary session (18.30 PARIS CET Time – 21.10 PARIS CET Time)** (Presentation of key messages and results of the SCD Patients Educational Session at ASCAT 2020 Plenary Session as conclusion of the Congress.) (10 min)