

## AGENDA

### Facilitating the creation of a bottom-up European Network of SCD Patients Organizations

**Monday 20<sup>th</sup> of December 2021, from 5 pm to 7 pm Paris CET time**

**05:00-05:10**

**Welcome and short introduction of each participant (10 min)**

*Maria del Mar Mañu Pereira (Scientific Director of the ERN-EuroBloodNet)*

**05:10- 05:15**

**Presentation of ePAGs (patient representatives) in the ERN-EuroBloodNet (5 min)**

*Ariane Weinman (EURORDIS)*

**05:15- 05:25**

**Presentation of the project “European Network of SCD Patients Organizations” by ERN-EuroBlood-Net and EURORDIS (10 min)**

*Mariangela Pellegrini (ERN-EuroBloodNet Educational & Patients Program Manager)*

**05:25-05:30**

**Why to encourage a Bottom-up European Network of Patients Organizations facilitated by the ERN and EURORDIS (5 min)**

*Loris Brunetta (ePAG ERN-EuroBloodNet)*

**05:30-05:40**

**Enhancing the collaboration between Patients and Provider to increase the advocacy for SCD in Europe (10 min)**

*Raffaella Colombatti (ERN-EuroBloodNet member)*

**05:40-07:00**

**Discussion with participants collecting feedback and answering questions on the establishment of a road map of priority actions to carry out collectively (1h20 min)**

*Moderator : Jan Geissler (ePAG ERN-EuroBloodNet) & Maria del Mar Mañu Pereira (Scientific Director of the ERN-EuroBloodNet)*