




# European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Neuromuscular  
Diseases (ERN EURO-NMD)

## AGENDA

### EURO-NMD EXECUTIVE COMMITTEE MEETING

**Monday 3rd October 2022**

**18:00 – 19.00 GMT+2 (Paris)**

<https://aim.zoom.us/meeting/register/tZ0qdu2upzgjE9S9Au9eAL7bEzwdP2viu6sl>

1. **Apologies:**  
**Montse Olivé Plana; Pierre Carlier; Cornelia Kornblum**
2. **AMEQUIS announce**
3. **Annual meeting:**
  - a. **where: Porto**
  - b. **when: 1-3 Feb 2023 (tbc)**
  - c. **Suggestions for overarching theme**
  - d. **Registry meeting in parallel?**
4. **WG motor neuron:**
  - a. **New chair? – last Exec decided to change the Chair – Action to be taken**
  - b. **Split SMA? – discussed in the Exec and request from Nice**
5. **Proposal Re-habilitation WG (Norway)**
6. **Thematic workshops with ENMC?:**
  - a. **Guidelines (eg, management of dysphagia in NMDs by M de Visser)**
  - b. **PROMs (eg, outcome measure for distal myopathies by L Maggi)**
  - c. **Patient journeys**
7. **inter-ERN Myto WG (request from Michelangelo)**
  - a. **Survey & financing of a guideline**
8. **AOB**

**Next Meeting: Monday 7th November 2022, 18:00-19:00 (Paris time)**

