

# ERN EURO-NMD 8<sup>TH</sup> ANNUAL MEETING

17 05, 06 and 07 March 2025

📍 Teaching and Learning Center (Lehr- und Lernzentrum), Virchowstraße 163a, 45147 Essen



European  
Reference  
Network

for rare or low prevalence  
complex diseases

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

● **Coordinator**  
Assistance Publique –  
Hôpitaux de Paris,  
Hôpital Pitié-Salpêtrière  
– France

## MEETING PROGRAMME

All plenary sessions take place in the Auditorium. Rooms are specified for other meetings.

### TIME

### DAY 1- WEDNESDAY, MARCH 5th

12:45-13:30

*Registration*

13:30 – 13:40

*Welcome note*

*Ulrike Schara-Schmidt and Teresinha Evangelista*

13:40 – 14:45

*Keynote lectures*

13:40 – 14:10

*Exercise and Neuromuscular Disorders – Nicole Voet  
(moderator: Kristin Ørstavik)*

14:10 – 14:20

*Discussion*

14:20 – 14:50

*Sleep and Neuromuscular Disorders – Matthias Boentert  
(moderator: Antonio Atalaia)*

14:50 – 15:00

*Discussion*

15:00-15:30

*Coffee Break*

TIME		DAY 1- WEDNESDAY, MARCH 5th				
15:30–16:00	<i>Panorama of devices for the non-invasive assessment of the neuromuscular systems - Jean-Yves Hogrel</i>					
16:00 – 16:30	<i>Patient reported outcome measures: PROMMY the new app in the PROMs’ ecosystem – Michelangelo Mancuso</i>					
16:30-17:00	<i>Landscape of gene therapy practices across Europe - Kleopas Kleopa</i>					
17:00-17:30	<i>Coffee Break</i>					
17:30 -19:00	<i>Parallel Working Groups Sessions</i>					
<b>Peripheral nerve diseases</b>	<b>Mitochondrial</b>	<b>Muscle Diseases</b>	<b>Neuromuscular Junction</b>	<b>Imaging</b>		
Pareyson and Kleopa	Mancuso and Kornblum	Marianne de Visser	Lochmuller and Maggi	P Carlier		
<b>Room 1</b>	<b>Room 2</b>	<b>Auditorium</b>	<b>Room 3</b>	<b>Room 4</b>		

<b>TIME</b>	<b>DAY 2 - THURSDAY, MARCH 6th</b>
08:45-10:00	<b><i>Transition of Care</i></b>
08:45 – 09:05	<b><i>Introduction and the Essen use case – Ulrike Schara-Schmidt and Tim Hagenacker</i></b>
09:05 – 09:20	<b><i>A French centre experience – Marion Masingue</i></b>
09:20 – 09:30	<b><i>EURO-NMD’s transition survey results – Teresinha Evangelista</i></b>
09:30 – 10:00	<b><i>Round Table “Transition according to patients’ needs”</i></b>
10:00-10:30	<b><i>Coffee Break</i></b>
10:30-12:30	<b><i>Presentation of Case Reports</i></b> <i>Moderated by Anna Kostera-Pruszczuk and Tanya Stojkovic</i>
12:30-13:30	<b><i>Lunch</i></b>
13:30 – 15:00	<b><i>EURO-NMD outreach activities</i></b> <i>Moderated by António Atalaia</i>
13:30 – 14:00	<b><i>NMD4C – interaction between neuromuscular networks – Hanns Lochmüller TBC</i></b>
14:00 – 14:30	<b><i>JARDIN – integration of ERN in National Health Systems – TBC</i></b>
14:30 – 15:00	<b><i>ERDERA – Funding and Clinical Research Network contributions for ERNs development– Gisèle Bonne</i></b>
15:00-15:30	<b><i>Coffee Break</i></b>
15:30 – 19:00	<b><i>Satellite Symposium: Newborn Screening</i></b> <i>This symposium is sponsored and the program is sent separately</i>
19:30 – 22:00	<b><i>Meeting dinner at Restaurant Hülsmannshof, Lehnsgrund 14a, 45149 Essen, <a href="http://www.huelsmannshof.de">www.huelsmannshof.de</a></i></b>

TIME		DAY 3- FRIDAY, MARCH 7th				
08:15 -09:45		<b><i>Parallel Working Groups Sessions</i></b>				
<b>Motor Neuron Disorders</b>	<b>Genetics</b>	<b>Neuropathology</b>	<b>Neurophysiology</b>	<b>Multidisciplinary Care</b>		
Kirschner/Silani	A Ferlini	E Malfatti	Bergh and Verhamme	M Nordstrøm		
<b>Room 1</b>	<b>Room 2</b>	<b>Auditorium</b>	<b>Room 3</b>	<b>Room 4</b>		
09:45 – 10:00		<b><i>Coffee Break</i></b>				
10:00 – 12:30		<b><i>Board Meeting</i></b>				
<i>Invitation only: the program is sent separately</i>						
12:30 – 13:30		<b><i>Lunch</i></b>				
<i>Invitation only</i>						