

ERN EURO-NMD 8TH ANNUAL MEETING

📅 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.

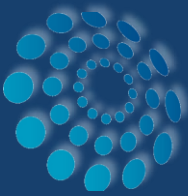
TIME	DAY 1- WEDNESDAY, MARCH 5th
12:45-13:30	Registration
13:30 – 13:40	Welcome note <i>Ulrike Schara-Schmidt and Teresinha Evangelista</i>
13:40 – 14:45	Keynote lectures
13:40 – 14:10	Exercise and Neuromuscular Disorders – Nicole Voet <i>(moderator: Kristin Ørstavik)</i>
14:10 – 14:20	Discussion
14:20 – 14:50	Sleep and Neuromuscular Disorders – Matthias Boentert <i>(moderator: Antonio Atalaia)</i>
14:50 – 15:00	Discussion
15:00-15:30	Coffee Break

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

TIME	DAY 2 - THURSDAY, MARCH 6th
08:45-10:00	<i>Transition of Care</i>
08:45 – 09:05	<i>Introduction and the Essen use case – Ulrike Schara-Schmidt and Tim Hagenacker</i>
09:05 – 09:20	<i>A French centre experience – Marion Masingue</i>
09:20 – 09:30	<i>EURO-NMD's transition survey results – Teresinha Evangelista</i>
09:30 – 10:00	<i>Round Table “Transition according to patients’ needs”</i>
10:00-10:30	<i>Coffee Break</i>
10:30-12:30	<i>Presentation of Case Reports</i> <i>Moderated by Anna Kostera-Pruszczyk and Tanya Stojkovic</i>
12:30-13:30	<i>Lunch</i>
13:30 – 15:00	<i>EURO-NMD outreach activities</i> <i>Moderated by António Atalaia</i>
13:30 – 14:00	<i>NMD4C – interaction between neuromuscular networks – Hanns Lochmüller</i>
14:00 – 14:30	<i>ECTN European Clinical Trials Network – Nicol Voermens and Ria de Haas</i>
14:30 – 15:00	<i>ERDERA – Funding and Clinical Research Network contributions for ERNs development– Gisèle Bonne</i>
15:00-15:30	<i>Coffee Break</i>
15:30 – 19:00	<i>Satellite Symposium: Newborn Screening</i> <i>This symposium will be sponsored (programme page 5)</i>
19:30 – 22:00	<i>Meeting dinner at Restaurant Hülsmannshof, Lehngrund 14a, 45149 Essen, www.huelsmannshof.de</i>

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

Thursday 06 March 2024, 15:30 – 19:00
Teaching and Learning Center
(Lehr- und Lernzentrum)
Virchowstraße 163a, 45147 Essen



Newborn Screening

Satellite Symposium organized by
EURO-NMD
European Reference Network for
Rare Neuromuscular Disorders

Agenda

15:30 – 15:40	Introduction – <i>Teresinha Evangelista</i>	APHP Paris, France
15:40 – 16:00	Screen4Care – <i>Alessandra Ferlini</i>	University Ferrara, Italy
16:00 – 16:20	NBS for Spinal Muscular Atrophy – <i>Jan Kirschner</i>	Uniklinikum Freiburg, Germany
16:20 – 16:40	SMA NBS seen by patients and carers - <i>Marie-Christine Ouillade</i>	AFM Théleton, France
16:40 – 17:00	Coffee Break	
17:00 – 17:20	NBS for DMD – <i>Elizabeth Vroom</i>	World Duchenne Organization
17:20 – 17:40	Cystic Fibrosis NBS: the German landscape - <i>Lutz Nährlich</i>	Pädiatrie und Neonatologie, Justus- Liebig-Universität Gießen, Germany
17:40 – 18:00	NBS for Rare Metabolic Diseases – <i>Maurizio Scarpa, Coordinator of MetabERN</i>	MetabERN, ERN for Rare Metabolic Diseases
18:00 – 18:20	NBS for Rare Diseases – <i>Gulcin Gumus</i>	EURORDIS
18:20 – 19:00	Discussion and Closing Remarks	