

ERN EURO-NMD 9th ANNUAL MEETING

📅 27, 28 and 29 April 2026

📍 Paris Brain Institute, Pitié-Salpêtrière
Hospital, Paris, France



**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

PRELIMINARY MEETING PROGRAMME

DAY 1 Monday, April 27th		
Time	Session	Speakers/Chairs
12:00 - 13:00	<i>Registration & Lunch</i> <i>The auditorium will be accessible at 12:30</i>	
13:00 - 13:30	Welcome Note	Teresinha Evangelista, APHP representative
13:30 - 15:00	Keynote lectures	Co-chairs: Anna Kostera-Pruszyk & Andreas Ziegler
13:30 - 14:15	Gene therapy in NMDs: Advances and Limitations	Kleopas Kleopa
14:15 - 15:00	Therapeutic applications and challenges in myostatin inhibition	Jan Kirschner
15:00 - 15:30	<i>Coffee break</i>	
15:30 - 16:50	Scientific Perspectives from the ERN EURO-NMD Working Groups (Session 1)	Co-chairs: Marianne de Visser, Anthony Béhin
15:30 - 15:50	Peripheral Nerve Diseases WG: Conduction blocks: at the evolving frontier between hereditary and autoimmune neuropathies	Gorka Fernandez
15:50 - 16:10	Neuromuscular Junction Disorders WG: Novel molecular therapies for Genetic Defects of the NMJ	Hanns Lochmüller
16:10 - 16:30	Muscle Diseases WG: Future Treatments for FSHD and DM1	Nicol Voermans
16:30 - 16:50	Mitochondrial Diseases WG:	Michelangelo Mancuso

	Updates on Mitochondrial Treatments	
16:50 - 17:20	<i>Coffee Break</i>	
17:20 - 18:45	Scientific Perspectives from the ERN EURO-NMD Working Groups (Session 2)	Co-chairs: Kristin Ørstavik, Gabriele Siciliano
17:20 - 17:45	Multidisciplinary Care and Management WG: Pregnancy in NMD	Marc Dommergues
17:45 - 18 :05	Motor Neuron Diseases WG: Mild motor impairment in presymptomatic ALS	Vincenzo Silani
18.05 - 18:25	Neurophysiology WG: Artificial Intelligence in Neurophysiology	Shahram Attarian
18:25 - 18:45	Neuromuscular Pathology WG: Myopathological HPO Terms for Muscle Biopsy Reporting	Edoardo Malfatti

DAY 2 Tuesday, April 28 th		
Time	Session	Speaker/Chairs
09:00 - 11:00	ERN EURO-NMD Board Meeting (Invitation only) <i>The detailed agenda will be sent separately</i>	TBD
11:00 - 11:30	<i>Coffee Break</i>	
11:30 - 12 :30	Scientific Perspectives from the ERN EURO-NMD Working Groups (Session 3)	Co-chairs: Eleni Zamba-Papanicolaou, Robert-Yves Carlier
11:30 - 11:50	Genetics WG: Synonymous variants: the geneticists' puzzle	Alessandra Ferlini
11:50 - 12:10	Neuromuscular Imaging WG: MR Imaging Pearls: Lessons from Misinterpretation	Pierre Carlier
12:10 - 12:30	Patient Advisory Board Activities and Perspectives	François Lamy
12:30 - 13:30	Lunch and Photo call	
13:30 - 14:30	The ERN EURO-NMD Registry	Peter-Bram Hoen and Teresinha Evangelista
13:30 - 13:45	Update on the registry (15')	TBD
13:45 - 14:00	Use case: Republic of Ireland (15')	TBD

14:00 - 14:15	Use case: Greece (15')	George Papadimas
14:15 - 14:30	Discussion (15')	TBD
14:30 - 15:00	<i>Coffee Break</i>	
15:00 - 18:30	<u>Satellite Scientific Symposium:</u> New therapeutic horizons in immune-mediated NMDs: from bench discoveries to bedside decisions <i>See the detailed programme on the last page of this document</i>	
20:00	<i>Networking Dinner (Invitation only)</i>	

DAY 3 | Wednesday April 29th

Time	Session			Speaker/Chairs
8:30 - 9:30	The Diagnostic Odyssey in NMDs: How can we do better?			Chair TBD
8:30 – 8:50	National Strategy and Lessons learned from the French experience			Shahram Attarian
8:50 - 9:05	How can we move forward at the European Level?			Teresinha Evangelista
9:05 – 9:30	Panel discussion			TBD
09:30 - 10:30	Presentation of Case Reports			Co-chairs: Tanya Stojkovic, Luis Querol
10:30 - 10:45	Closing remarks - End of the Plenary programme			Teresinha Evangelista
10:45 - 11:15	<i>Coffee Break</i>			
11:15 – 13:15	Parallel Working Groups Sessions			
11:15 – 12:15	Neuromuscular pathology	Muscle	Mitochondrial diseases	Motor Neuron diseases
12:15 – 13:15	Multidisciplinary care	NMJ disorders	Peripheral nerve/Neurophysiology	Imaging
13:30 - 14:30	<i>Lunch and departure</i>			

ERN EURO-NMD Satellite Scientific Symposium:

New therapeutic horizons in immune-mediated NMDs: from bench discoveries to bedside decisions

Tuesday 28 April 2026, 15:00 – 18:30

Co-chairs: Anna Kostera-Pruszczyk, Hanns Lochmüller

Time	Topic	Speaker
15:00 - 15:10	Introduction	Teresinha Evangelista (ERN coordinator)
15:10 - 15:35	Defining meaningful outcome measures in the context of patient access to innovative therapies	Lutgarde Allard (EuMGA, Belgium)
15:35 - 15:50	Immunotherapies for NMDs: Recent advances and remaining challenges	Kristl Claeys (UZ Leuven, Belgium)
15:50 – 16:05	Pathophysiological targets in myasthenia gravis	Jan Verschuuren (LUMC, Netherlands)
16:05 – 16:25	Practical approaches for treatment selection in adult Myasthenia Gravis	Anthony Béhin (AP-HP, Paris)
16:25 – 16:45	Coffee break	
16:45 – 17:05	Current therapeutic strategies in pediatric MG	Sithara Ramdas (Oxford, UK)
17:05 – 17:35	Optimising treatment in immune-mediated myopathies: current evidence and gaps	Olivier Benveniste (APHP, Paris)
17:35 – 18:00	Inflammatory myopathies in children	Ulrike Schara-Schmidt (Essen University Hospital, Germany)
18:00 – 18:25	50 Years of CIDP: achievements and future perspectives	Shahram Attarian (APHM, Marseille)
18:25 – 18:30	Conclusion	Teresinha Evangelista