

# ERN EURO-NMD 9<sup>th</sup> 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 (V.6\_Feb 3<sup>rd</sup>, 2026)

DAY 1   Monday, April 27th		
Time	Session	Speakers/Chairs
12:00 - 13:00	<b>Registration &amp; Lunch</b> <i>The auditorium will be accessible at 12:30</i>	
13:00 - 13:30	Welcome Note	Teresinha Evangelista, APHP representative
13:30 - 15:00	<b>Keynote lectures</b>	Co-chairs: Anna Kostera-Pruszczyk & 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	<b>Coffee break</b>	
15:30 - 16:50	<b>Scientific Perspectives from the ERN EURO-NMD Working Groups (Session 1)</b>	Co-chairs: Marianne de Visser, Anthony Béhin
15:30 - 15:50	<b>Peripheral Nerve Diseases WG:</b> Conduction blocks: at the evolving frontier between hereditary and autoimmune neuropathies	Gorka Fernandez
15:50 - 16:10	<b>Neuromuscular Junction Disorders WG:</b> Novel molecular therapies for Genetic Defects of the NMJ	Hanns Lochmüller
16:10 - 16:30	<b>Muscle Diseases WG:</b> Future Treatments for FSHD and DM1	Massimiliano Filosto

16:30 - 16:50	<b>Mitochondrial Diseases WG:</b> Updates on Mitochondrial Treatments	Michelangelo Mancuso
16:50 - 17:20	<i>Coffee Break</i>	
17:20 - 18:45	<b>Scientific Perspectives from the ERN EURO-NMD Working Groups (Session 2)</b>	Co-chairs: Kristin Ørstavik, Gabriele Siciliano
17:20 - 17:45	<b>Multidisciplinary Care and Management WG:</b> Pregnancy in NMD	Marc Dommergues
17:45 - 18 :05	<b>Motor Neuron Diseases WG:</b> Mild motor impairment in Presymptomatic ALS	Vincenzo Silani
18.05 - 18:25	<b>Neurophysiology WG:</b> Artificial Intelligence in Neurophysiology	Shahram Attarian
18:25 - 18:45	<b>Neuromuscular Pathology WG:</b> Myopathological HPO Terms for Muscle Biopsy Reporting	Edoardo Malfatti

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

14:00 - 14:15	Use case: Greece	George Papadimas
14:15 - 14:30	Discussion	Peter-Bram Hoen and Teresinha Evangelista
14:30 - 15:00	<i>Coffee Break</i>	
15:00 - 18:30	<p align="center"><u>Satellite Scientific Symposium:</u>  <b>New therapeutic horizons in immune-mediated NMDs: from bench discoveries to bedside decisions</b>  <i>See the detailed programme on the last page of this document</i></p>	
20:00	<i>Networking Dinner (Invitation only)</i>	

DAY 3   Wednesday April 29 <sup>th</sup>				
Time	Session			Speaker/Chairs
8:30 - 9:30	<b>The Diagnostic Odyssey in NMDs: How can we do better?</b>			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	<b>Presentation of Case Reports</b>			Co-chairs: Tanya Stojkovic, Elena Pegoraro
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	<b>Parallel Working Groups Sessions</b>			
11:15 – 12:15	Neuromuscular pathology	Muscle	Mitochondrial diseases	Motor Neuron diseases
12:15 – 13:15	Multidisciplinary care	NMJ disorders	Peripheral nerve/Neurophysiology	Imaging
<b>EXTRA 15 MINS LEFT (in case needed)</b>				
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	<i>Coffee break</i>	
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	<i>Conclusion</i>	Teresinha Evangelista (ERN coordinator)