

ERN EURO-NMD ANNUAL MEETING



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

📅 21, 22 and 23 February 2024

📍 Hôpital de la Pitié-Salpêtrière
Paris, France

PRELIMINARY MEETING PROGRAMME

DAY 1 - WEDNESDAY, FEBRUARY 21 st					
Time	Session				
12:45 - 13:30	Registration				
13:30 - 13:45	Welcome note Teresinha Evangelista				
13:45 - 14:45	Presentation of the ERN EURO-NMD activities				
13:45 - 14:00	Education Teresinha Evangelista 10' + 5' <i>discussion</i>				
14:00 - 14:15	CPMS Alessandra Ferlini 10' + 5' <i>discussion</i>				
14:15 - 14:30	Guidelines Michelangelo Mancuso 10' + 5' <i>discussion</i>				
14:30 - 14:45	EMQN scheme Carla d'Angelo 10' + 5' <i>discussion</i>				
14:45 - 15:45	Update on the EURO-NMD diseases working groups 40' + 15' <i>discussion</i>				
15:45 - 16:00	Break				
16:00 - 16:20	News from the PAB François Lamy				
16:20 - 17:20	Update on inter-ERN activities Moderators to be confirmed				
16:20 - 16:35	Gene therapy Kleopas Kleopa 10' + 5' <i>discussion</i>				
16:35 - 16:50	Postgraduate Curriculum on NMDs Marianne de Visser 10' + 5' <i>discussion</i>				
16:50 - 17:05	Mitochondrial diseases Michelangelo Mancuso 10' + 5' <i>discussion</i>				
17:05 - 17:20	Channelopathies (tbd) 10' + 5' <i>discussion</i>				
17:20 - 17:25	Break - Room change				
17:25 - 18:30	Parallel working groups session				
	<table border="1"> <tr> <td>Peripheral nerve diseases Davide Pareyson</td> <td>Mitochondrial diseases Michelangelo Mancuso & Cornelia Kornblum</td> <td>Genetics Alessandra Ferlini</td> <td>Patient Advisory Board (invitation only) François Lamy</td> </tr> </table>	Peripheral nerve diseases Davide Pareyson	Mitochondrial diseases Michelangelo Mancuso & Cornelia Kornblum	Genetics Alessandra Ferlini	Patient Advisory Board (invitation only) François Lamy
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End of the Day 1 plenary programme					
18:30 - 19:30	Registry group meeting (invitation only)				

DAY 2 - THURSDAY, FEBRUARY 22nd

Time	Session
08:45 - 09:45	Registry plenary session
09:45 - 10:45	Update on European projects Moderated by Hanns Lochmüller and Shahram Attarian
09:45 - 10:00	ERICA Ana Rath (Orphanet - INSERM US14)
10:00 - 10:15	ERDERA/Rare Diseases Partnership Yanis Mimouni (EJP-RD)
10:15 - 10:30	Screen4Care Alessandra Ferlini
10:30 - 10:45	Discussion
10:45 - 11:00	Break
11:00 - 13:00	Newborn screening session Moderated by Susanna Quijano and Ulrike Shara-Schmidt
11:00 - 11:30	Current and future perspectives on NBS Jim Bonham 20' + 10' discussion
11:30 - 12:00	Role of the NMDs community in NBS Manuela Santos 20' + 10' discussion
12:00 - 12:15	Role of ERNs in developing NBS policies Jan Kirschner 10' + 5' discussion
12:15 - 12:30	NBS workpackage in the Screen4care project Jan Kirschner 10' + 5' discussion
12:30 - 13:00	Patients perspective Marie-Christine Ouillade 20' + 10' discussion
13:00 - 14:00	Lunch
14:00 - 14:15	Photo call
14:15 - 15:30	Presentation of case reports
15:30 - 15:45	Closing remarks
15:45 - 16:00	Break
16:00 - 19:00	Satellite scientific symposium: Present and future of gene therapy in neuromuscular diseases (Detailed programme to be communicated on a later date)
19:00 - 19:30	End of the Day 2 programme - Networking

DAY 3 - FRIDAY, FEBRUARY 23 rd			
Time	Session		
08:30 - 09:45	Parallel working groups session		
	<table border="1"> <tr> <td> Motor neuron diseases & Multidisciplinary management and care Jan Kirschner, Vincenzo Silani, Marianne Nordstrøm </td> <td> Muscle diseases Marianne de Visser </td> </tr> </table>	Motor neuron diseases & Multidisciplinary management and care Jan Kirschner, Vincenzo Silani, Marianne Nordstrøm	Muscle diseases Marianne de Visser
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09:45 - 10:00	Break		
10:00 - 12:30	Board meeting (invitation only)		
12:30 - 13:30	Lunch (invitation only)		
14:00	End of the programme		