

Summer School

Multidisciplinary management of Neuromuscular diseases

24 – 27 September 2025, Marseille, France

PROGRAMME

WEDNESDAY 24 SEPTEMBER		
Time	Session	
14:30 – 15:00	Arrival to the venue and registration	
15:00 – 15:45	Welcome and introduction session	
	15:00 – 15:30	Overview and objectives of the programme Presentation of the ERN EURO-NMD and FILNEMUS <i>Teresinha Evangelista and Shahram Attarian</i>
	15:30 – 15:45	Introductory round <i>Students and Faculty</i>
15:45 – 19:00	Why multidisciplinary care for NMD patients is essential <i>Chaired by Teresinha Evangelista and Shahram Attarian</i>	
	15:45 – 16:15	Overview of neuromuscular diseases <i>Teresinha Evangelista</i>
	16:15 – 16:45	Focus on neuropathies and motor neuron diseases <i>Shahram Attarian</i>
	16:45 – 17:00	Coffee/tea break
	17:00 – 17:45	Focus on myopathies, neuromuscular junction defects and mitochondrial diseases <i>Marianne de Visser</i>
	17:45 – 18:45	Patient journeys <i>Jean-Philippe Plançon</i>
	18:45 – 19:00	Discussion

THURSDAY 25 SEPTEMBER

Time	Session						
09:00 – 09:45	<p>Cardiac involvement <i>Karim Wahbi</i></p> <p>This session will cover cardiac assessments, cardiomyopathy and heart failure management, and strategies for preventing arrhythmias and sudden death.</p>						
09:45 – 10:30	<p>Endocrinological involvement <i>Kristl Claeys</i></p> <p>This session will address endocrinological aspects of NMDs encompassing mitochondrial myopathies, Kennedy's disease, and SMA, as well as the need for endocrinological care arising from steroid treatment in patients with immune-mediated NMDs (such as immune-mediated polyneuropathies, myositis, and myasthenia gravis).</p>						
10:30 – 11:00	Coffee/tea break						
11:00 – 12:00	<p>Gastrointestinal involvement <i>Chaired by Marianne Nordstrøm</i></p>						
	<table border="1"> <tr> <td style="width: 150px;">11:00 – 11:25</td> <td>Dysphagia, speech and language <i>Mieke Kooi</i></td> </tr> <tr> <td>11:25 – 11:45</td> <td>Nutrition <i>Marianne Nordstrøm</i></td> </tr> <tr> <td>11:45 – 12:00</td> <td>Lower gastrointestinal tract <i>Marianne Nordstrøm</i></td> </tr> </table>	11:00 – 11:25	Dysphagia, speech and language <i>Mieke Kooi</i>	11:25 – 11:45	Nutrition <i>Marianne Nordstrøm</i>	11:45 – 12:00	Lower gastrointestinal tract <i>Marianne Nordstrøm</i>
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11:45 – 12:00	Lower gastrointestinal tract <i>Marianne Nordstrøm</i>						
12:00 – 12:45	<p>Dysautonomia <i>Davide Pareyson</i></p> <p>This session will explore the pathophysiology of autonomic dysfunction across the sympathetic, parasympathetic, and enteric systems, associated symptoms, tools and tests used for diagnosis and assessment, as well as current approaches to management and therapy.</p>						
12:45 – 13:45	Lunch						
13:45 – 14:30	<p>Central nervous system involvement and epilepsies <i>Michelangelo Mancuso</i></p> <p>This session will address CNS involvement in various myopathies including mitochondrial myopathy, myotonic dystrophy, Duchenne muscular dystrophy, and Congenital muscular dystrophy.</p>						
14:30 – 15:30	<p>Respiratory involvement <i>Chaired by H�el�ene Prigent</i></p>						

	14:30 – 15:00	Physiopathology and management of respiratory failure in NMDs <i>Hélène Prigent</i> This topic includes mechanical ventilation, airway clearance, and specificities of ventilator-dependent patient management (mouth piece ventilation and tracheostomy indication)
	15:00 – 15:20	Specificities in respiratory management of paediatric patients <i>Jessica Tayard</i>
	15:20 – 15:30	Discussion
15:30 – 16:00	Coffee/tea break	
16:00 – 17:30	Rehabilitation <i>Chaired by Isabelle Desguerre</i>	
	16:00 – 16:30	Exercise, pain and fatigue <i>Nicole Voet</i>
	16:30 – 16:50	Musculoskeletal involvement <i>Susana Quijano-Roy</i>
	16:50 – 17:10	Orthotics <i>Viola Altmann</i>
	17:10 – 17:30	Discussion
19:30	Faculty dinner	

FRIDAY 26 SEPTEMBER		
Time	Session	
09:00 – 09:30	Skin involvement <i>Olivier Benveniste</i>	
09:30 – 10:00	Management of relationships and sexuality in NMDs <i>Rui Machado</i>	
10:00 – 10:30	Management of pregnancy in NMD patients <i>Marianne de Visser</i>	
10:30 – 11:00	Coffee/tea break	
11:00 – 12:00	Palliative care <i>Chaired by Marianne de Visser</i>	
	11:00 – 11:20	Amyotrophic lateral sclerosis <i>Vincenzo Silani</i>

	11:20 – 11:50	Other NMDs <i>Isabelle Desguerre and Kristin Ørstavik</i>
	11:50 – 12:00	Discussion
12:00 – 12:20	Highlights of the programme <i>Daive Pareyson</i>	
12:20 – 13:15	Lunch	
13:15 – 14:45	Organization of care <i>Chaired by Isabelle Desguerre and Shahram Attarian</i>	
	13:15 – 14:00	Presentation of survey results on access to multidisciplinary care and childhood/adult transition in European countries <i>Houda Ali</i>
	14:00 – 14:45	Panel discussion with experts representing different countries
14:45 – 15:30	Psychological impact and burden of NMDs <i>Chaired by Susana Quijano-Roy and Emmanuelle Salort-Campana</i>	
	14:45 – 15:15	Delivering the diagnosis Burden on carers and helpers <i>Nathalie Angeard</i>
	15:15 – 15:30	Patients' perspective <i>Jean-Philippe Plançon and Arabela Acalinei</i>
	15:30 – 15:40	Discussion
15:40 – 16:00	Coffee/tea break	
16:00 – 18:00	Serious game: delivering the diagnosis <i>Chaired by Vincenzo Silani and Nathalie Angeard</i> Students will be asked to play the role of a doctor or a patient in different scenarios around the announcement of the diagnosis, and will receive feedback from the experts in attendance (clinicians and patients).	
19:30	Conference dinner	

SATURDAY 27 SEPTEMBER

Time	Session
09:00 – 11:00	Hands-on session: Presentation of clinical cases <i>Chaired by Susana Quijano-Roy and Emmanuelle Salort-Campana</i> Students will be divided into separate groups, with each group tasked to present a predefined clinical case incorporating elements covered during the programme.
11:00 – 12:00	Feedback session <i>Chaired by Teresinha Evangelista and Shahram Attarian</i> Students will be divided into separate groups and tasked with preparing a few slides to offer feedback on a set of predefined questions. They will then present their feedback to both their peers and the faculty.
12:00 – 13:00	Lunch - End of the programme