

Summer school

Multidisciplinary management of Neuromuscular Diseases

12 - 14 September 2024, Marseille, France

Preliminary programme

THURSDAY 12 SEPTEMBER		
Time	Session	
09:00 – 09:45	Welcome	
	09:00 – 09:30	Overview and objectives of the programme Presentation of the ERN EURO-NMD and FILNEMUS <i>Teresinha Evangelista & Shahram Attarian</i>
	09:30 – 09:45	Introductory round <i>Students and Faculty</i>
09:45 – 10:45	Introduction: Why multidisciplinary care for NMD patients is essential	
	09:45 – 10:00	Overview of neuromuscular diseases <i>Shahram Attarian</i>
	10:00 – 10:15	Focus on neuropathies and motor neuron diseases <i>Shahram Attarian</i>
	10:15 – 10:30	Focus on myopathies, neuromuscular junction defects and mitochondrial diseases <i>Marianne de Visser</i>
	10:30 – 10:45	Discussion
10:45 – 11:15	Coffee/tea break - Networking	
11:15 – 12:00	Patient journey <i>Jean-Philippe Plançon</i>	

12:00 – 12:30	Cardiac involvement <i>Karim Wahbi</i> This session will cover cardiac assessments for patients, cardiomyopathy and heart failure management, and strategies for preventing arrhythmias and sudden death.	
12:30 – 13:30	Lunch	
13:30 – 14:00	Endocrinological involvement <i>Kristl Claeys</i> This session will address endocrinological aspects of NMDs encompassing mitochondrial myopathies, Kennedy's disease, and SMA, as well as the necessity for endocrinological care arising from steroid treatment in patients with immune-mediated NMDs (such as polyneuropathies, myositis, and myasthenia).	
14:00 – 15:00	Gastrointestinal involvement	
	14:00 – 14:20	Dysphagia, speech and language <i>Mieke Kooi</i>
	14:20 – 14:35	Nutrition <i>Marianne Nordstrøm</i>
	14:35 – 14:45	Lower gastrointestinal tract <i>Marianne Nordstrøm</i>
	14:45 – 15:00	Discussion
15:00 – 15:30	Dysautonomia <i>Davide Pareyson</i>	
15:30 – 16:00	Coffee/tea break	
16:00 – 16:30	Central nervous system involvement and epilepsies <i>Cornelia Kornblum</i> This session will address CNS involvement in various myopathies including mitochondrial myopathy, myotonic dystrophy, Duchenne muscular dystrophy, and Congenital muscular dystrophy.	
16:30 – 17:30	Respiratory involvement	
	16:30 – 17:00	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)
	17:00 – 17:20	Specificities in respiratory management of paediatric patients <i>Jessica Taytard</i>

	17:20 – 17:30	Discussion
19:30	Faculty dinner	

FRIDAY 13 SEPTEMBER		
Time	Session	
09:00 – 10:30	Rehabilitation	
	09:00 – 09:20	Exercise, pain and fatigue <i>Nicole Voet</i>
	09:20 – 09:50	Transition of care (childhood/adolescence to adulthood) <i>Kristl Claeys, other speaker to be determined</i>
	09:50 – 10:10	Musculoskeletal involvement <i>Susana Quijano-Roy</i>
	10:10 – 10:30	Discussion <i>Chaired by Isabelle Desguerre</i>
10:30 – 11:00	Coffee/tea break - Networking	
11:00 – 12:00	Palliative care	
	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 – 12:15	Highlights of the programme <i>Davide Pareyson</i>	
12:15 – 13:15	Lunch	
13:15 – 14:45	Organization of care	
	13:15 – 14:00	Presentation of the results of a survey investigating challenges and lessons learned in different countries <i>Isabelle Desguerre</i>

	14:00 – 14:45	Panel discussion with experts representing different countries <i>Chaired by Teresinha Evangelista & Shahram Attarian</i>
14:45 – 15:30	Psychological impact and burden of NMDs	
	14:45 – 15:05	Delivering the diagnosis Burden on carer and helpers <i>To be determined</i>
	15:05 – 15:20	Patients' perspective <i>Jean-Philippe Plançon and François Lamy</i>
	15:20 – 15:30	Discussion
15:30 – 16:00	Coffee/tea break - Networking	
16:00 – 18:00	Serious game: delivering the diagnosis 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 14 SEPTEMBER	
Time	Session
09:00 – 10:30	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.
10:30 – 10:45	Coffee/tea break
10:45 – 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