

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 and Shahram Attarian</i>
	09:30 – 09:45	Introductory round <i>Students and Faculty</i>
09:45 – 10:45	Why multidisciplinary care for NMD patients is essential <i>Chaired by Teresinha Evangelista and Shahram Attarian</i>	
	09:45 – 10:00	Overview of neuromuscular diseases <i>Teresinha Evangelista</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 journeys <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 <i>Chaired by Marianne Nordstrøm</i>	
	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 <i>Chaired by H��l��ne Prigent</i>	
	16:30 – 17:00	Physiopathology and management of respiratory failure in NMDs <i>H��l��ne 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 <i>Chaired by Isabelle Desguerre</i>	
	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 and Ulrike Schara-Schmidt (online)</i>
	09:50 – 10:10	Musculoskeletal involvement <i>Susana Quijano-Roy</i>
	10:10 – 10:30	Discussion
10:30 – 11:00	Coffee/tea break - Networking	
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 – 12:15	Highlights of the programme <i>Davide Pareyson</i>	
12:15 – 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 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 – 15:05	Delivering the diagnosis Burden on carer and helpers <i>Nathalie Angeard</i>
	15:05 – 15:20	Patients' perspective <i>Jean-Philippe Plançon and Arabela Acalinei</i>
	15:20 – 15:30	Discussion
15:30 – 16:00	Coffee/tea break - Networking	
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 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