European Reference Network
for rare or low prevalence complex diseases
Network Neuromuscular Diseases (ERN EURO-NMD)

Filnemus
Filière Neuromusculaire

Summer School
Multidisciplinary management of Neuromuscular diseases

21 – 24 October 2026, Marseille, France

Objectives

This programme addresses the full clinical pathway for neuromuscular disease (NMD) patients, highlighting the importance of multidisciplinary care beyond the neuromuscular field.

Participants will benefit from insights shared by a diverse faculty, including clinicians, allied health professionals, and patient representatives. The programme also emphasizes communication in sensitive contexts, such as diagnosis and palliative care, with dedicated sessions (including interactive sessions) to reflect real patient experiences.

Attendees will gain practical knowledge and perspectives that can be directly applied in their practice to support multidisciplinary care.

⚠ This course is NOT intended to provide basic teaching on NMDs or their treatments.

Scientific committee

- **Teresinha Evangelista**, AP-HP – Hôpital Pitié-Salpêtrière, Paris, France
- **Shahram Attarian**, AP-HM- Hôpital de la Timone, Marseille,
- **Marianne Nordstrøm**, University of Oslo, Norway
- **Marianne de Visser**, Amsterdam University Medical Center, The Netherlands
- **Davide Pareyson**, Fondazione IRCCS Istituto Neurologico C.Besta, Milan, Italy
- **Isabelle Desguerre**, AP-HP – Hôpital Necker, Paris, France
- **Jean-Philippe Plançon**, AFNP, EPODIN – La Baule-Escoublac, France
- **Hélène Prigent**, AP-HP – Hôpital Raymond-Poincaré, Garches, France
- **Karim Wahbi**, AP-HP- Hôpital Cochin, Paris, France

U.E.M.S.

The **Summer school on Multidisciplinary management of neuromuscular diseases, Marseille, France 21/10/2026 - 24/10/2026**, has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) with **18.5** European CME credits (ECMEC®s). Each medical specialist should claim only those hours of credit that he/she actually spent in the educational activity.

PROGRAMME

WEDNESDAY 21 OCTOBER 2026		
Time	**Session**	
14:30 – 15:00	**Arrival to the venue and registration**	
15:00 – 16:15	**Welcome and introduction session**	
	15:00 – 15:20	Overview and objectives of the programme Presentation of the ERN EURO-NMD and FILNEMUS *Teresinha Evangelista and Shahram Attarian*
	15:20 – 15:50	Ice breaker *Students and Faculty*
	15:50 – 16:15	Clinical case: setting the scene *Susana Quijano-Roy*
16:15 – 18:00	**Why multidisciplinary care for NMD patients is essential** *Chaired by Teresinha Evangelista and Shahram Attarian*	
	16:15 – 16:30	Overview of neuromuscular diseases *Teresinha Evangelista*
	16:30 – 17:00	Focus on neuropathies and motor neuron diseases *Shahram Attarian*
	17:00 – 17:15	**Break**
	17:15 – 18:00	Focus on myopathies, neuromuscular junction defects and mitochondrial diseases *Marianne de Visser*
18:00 – 18:45	**Endocrinological involvement in NMDs** *Kristl Claeys (online)* 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).	

THURSDAY 22 OCTOBER 2026	
Time	**Session**
09:00 – 09:30	**Multidisciplinary care in NMDs: a Patient perspective on holistic care** *Jean-Philippe Plançon* This presentation will explore how patient experience can inform multidisciplinary care, addressing medical, functional, psychological and social needs. Examples from inflammatory neuropathies and the EURO-NMD Patient Journeys project will illustrate key challenges and opportunities for coordinated, person-centred care.
09:30 – 10:15	**Cardiac involvement** *Karim Wahbi* This session will cover cardiac assessments, cardiomyopathy and heart failure management, and strategies for preventing arrhythmias and sudden death in muscular dystrophies.
10:15 – 10:45	**Break**
10:45 – 11:45	**Nutrition, Dysphagia and Gastrointestinal involvement** *Marianne Nordstrøm and Mieke Kooi* This session will cover dysphagia and speech-related disorders, nutritional assessment and management, and lower gastrointestinal dysfunction in NMDs. It will address clinical challenges and multidisciplinary care strategies.
11:45 – 12:30	**Dysautonomia** *Davide Pareyson* This session will explore the pathophysiology of autonomic dysfunction across the sympathetic and parasympathetic systems, associated symptoms, tools and tests used for diagnosis and assessment, as well as current approaches to management and therapy.
12:30 – 13:30	**Lunch**
13:30 – 14:15	**Central nervous system involvement and epilepsies** *Jens Reimann* This session will address CNS involvement in various myopathies including mitochondrial myopathy, myotonic dystrophy, Duchenne muscular dystrophy, and Congenital muscular dystrophy.
14:15 – 15:20	**Respiratory involvement** *Chaired by Hélène Prigent* This session will address the mechanisms of respiratory involvement in NMDs and its management (including mechanical ventilation an airway clearance techniques). Specific management of pediatric patients and ventilator-dependent patients will also be discussed.

	14:15 – 14:45	Physiopathology and management of respiratory failure in NMDs *Hélène Prigent*
	14:45 – 15:10	Specificities in respiratory management of paediatric patients *Jessica Taytard*
	15:10 – 15:20	Discussion
15:20 – 15:45	**Break**	
15:45 – 17:30	**Rehabilitation** *Chaired by Isabelle Desguerre* This session will explore the role of exercise in managing pain and fatigue, the assessment and management of musculoskeletal complications, and the use of orthotics to support mobility and function. It will highlight practical approaches to maintaining independence and quality of life through multidisciplinary rehabilitation strategies.	
	15:45 – 16:15	Exercise, pain and fatigue *Nicole Voet*
	16:15 – 16:40	Musculoskeletal involvement *Susana Quijano-Roy*
	16:40 – 17:10	Orthotics *Nicole Voet*
	17:10 – 17:30	Discussion
19:30	**Faculty dinner**	

FRIDAY 23 OCTOBER 2026	
Time	**Session**
09:00 – 09:30	**Skin involvement** *Olivier Benveniste* This session will examine dermatological manifestations associated with NMDs and how characteristic skin findings can provide valuable diagnostic clues and insights into underlying systemic involvement.
09:30 – 10:00	**NMDs in practice: Five interactive clinical cases** *Teresinha Evangelista* Five clinical cases involving different diseases will be presented, inviting participants to engage in clinical decision-making, share their perspectives and discuss diagnostic and management challenges.

10:00 – 10:30	**Management of pregnancy in NMD patients** *Marianne de Visser* This session will discuss the obstetric issues and neonatal outcome in various neuromuscular diseases, such as myotonic dystrophy and myasthenia gravis.	
10:30 – 11:00	**Break**	
11:00 – 12:10	**Palliative care** *Chaired by Marianne de Visser and Nathalie Angeard* This session will explore the principles of supportive care, and communication with patients and families about symptom management, highlighting the importance of a multidisciplinary approach throughout the course of the disease.	
	11:00 – 11:30	Palliative care and advanced care planning *Isabelle Desguerre and Kristin Ørstavik*
	11:30 – 11:50	Amyotrophic lateral sclerosis *Vincenzo Silani*
	11:50 – 12:10	Discussion
12:10 – 12:30	**Highlights of the programme** *Davide Pareyson* This concluding session will highlight the key messages and lessons learned from the different topics addressed throughout the programme, summarizing the main insights on multidisciplinary care in NMDs.	
12:30 – 13:30	**Lunch and Photo call**	
13:30 – 14:30	**Transition of care from paediatric to adult services** *Chaired by Isabelle Desguerre and Shahram Attarian*	
	13:30 – 13:50	Presentation of results from the ERN EURO-NMD survey on Transition from childhood to adulthood in NMDs *Teresinha Evangelista*
	13:50 – 14:30	Panel discussion with experts representing different countries
14:30 – 15:30	**Psychological impact and burden of NMDs** *Chaired by Susana Quijano-Roy and Emmanuelle Salort-Campana* This session will address the psychological and emotional impact of NMDs on patients and their families, including the challenges of delivering the diagnosis, caregiver burden, and the lived experience of patients.	
	14:30 – 14:45	The Patient experience *Jean-Philippe Plançon*

	14:45 – 15:15	Delivering the diagnosis Burden on carers and helpers *Nathalie Angeard*
	15:15 – 15:30	Discussion *Nathalie Angeard, Marianne Nordstrøm and Jean-Philippe Plançon*
15:30 – 16:00	**Break**	
16:00 – 18:00	**Serious game: delivering the diagnosis** *Chaired by Vincenzo Silani and Nathalie Angeard* Students will work in groups and reenact different scenarios related to the announcement of a diagnosis, taking on the key roles involved in each situation, followed by feedback and discussion with the experts in attendance (clinicians and patients).	
19:30	**Conference dinner**	

SATURDAY 24 OCTOBER 2026	
Time	**Session**
09:00 – 11:00	**Hands-on session: Presentation of clinical cases** *Chaired by Susana Quijano-Roy and Emmanuelle Salort-Campana* 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** *Chaired by Teresinha Evangelista and Shahram Attarian* 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**