

## Myotonic Dystrophy Peer to Peer Program

### SCIENTIFIC RATIONALE

Myotonic Dystrophy is amongst the most variable neuromuscular condition ranging from congenital onset to late-adult onset. It is a multiorgan disease affecting well beyond skeletal muscle, the heart, respiratory muscles, the eye, the gastrointestinal system and the CNS being variably dysfunctional in the disease, depending on the age, the type of onset and the duration of disease. Natural history studies are guiding clinical care towards the best outcomes to develop and apply in monitoring the disease and designing clinical trials. While this is in a more advanced phase in adults with DM1, there are more challenges in the pediatric onset phenotypes. The transition from pediatric to adult care in Myotonic Dystrophy Type 1 (DM1) represents a pivotal phase for individuals diagnosed with congenital or juvenile-onset forms of the disease. This stage, like the adult phenotype stage, demands a multidisciplinary, integrated, and anticipatory approach designed to meet the evolving clinical complexity and life circumstances of young adults.

This Peer-to-Peer educational program is built to foster clinical collaboration, facilitate the exchange of best practices, and provide practical, case-based insights into the management of DM1. Through immersive sessions with experienced care teams, the program explores strategies for managing the multisystemic manifestations of DM1—including neuromuscular, cardiac, respiratory, gastrointestinal, cognitive, and endocrine involvement. The agenda is structured around: individualized and proactive care pathways; the roles and coordination of multidisciplinary teams, and future-forward models for long-term disease monitoring and functional support. Particular emphasis is placed on the early recognition of systemic complications and the optimization of care before irreversible decline occurs—a principle that becomes essential in the era of emerging therapeutic approaches. Ensuring excellence in Standards of Care (SoC) is key not only to improving current outcomes, but also to enhancing the potential benefits of future pharmacological interventions in DM1.



Educational credits: 14,2



This event has been accredited by the  
**European Accreditation Council for Continuing Medical Education (EACCME®)**  
with **11.5 European CME credits (ECMEC®s)**.

Each medical specialist should claim only those hours of credit  
that he/she actually spent in the educational activity

Unrestricted educational grant



Provider ECM



Via Paolo Lomazzo, 34 - 20154 Milano  
Ph. +39 02 40029228  
info@educo-ecm.it

Organizing Secretariat



Via Vittoria Colonna 40, 20149 Milano  
Ph. +39 02 30066329  
info@fclassevents.com

## Myotonic Dystrophy Peer to Peer Program

21<sup>st</sup> - 22<sup>nd</sup> November 2025  
The NeMO Clinical Center - Milan, Italy



SCIENTIFIC COORDINATOR:

**Valeria Sansone**

*Clinical and Scientific Director NeMO Clinical Center,  
Full Professor of Neurology, University of Milan*



CENTRO CLINICO  
**Nemo**

# Myotonic Dystrophy Peer to Peer Program

## FACULTY

**Agliuzzo Claudia**  
*Rehabilitation Specialist, NeMO Clinical Center*

**Albamonte Emilio**  
*Child Neurologist, NeMO Clinical Center*

**Bazzoni Elena**  
*Nurse Coach, NeMO Clinical Center*

**Birman Nurit**  
*Neurologist, NeMO Clinical Center*

**Cattaneo Camilla**  
*Speech and Language Therapist, NeMO Clinical Center*

**Cima Alessandra**  
*Rehabilitation Specialist, NeMO Clinical Center*

**Colacicco Giovanni**  
*Neurologist, NeMO Clinical Center*

**Croci Massimo**  
*Pulmonologist, NeMO Clinical Center*

**Ferrari Aggradi Carola**  
*Neurologist, NeMO Clinical Center*

**Gotti Elena**  
*Nurse Coach, NeMO Clinical Center*

**Greco Alessio**  
*Geriatrician, NeMO Clinical Center*

**Pozzi Susanna**  
*Clinical psychologist, NeMO Clinical Center*

**Roma Elisabetta**  
*Pulmonologist, NeMO Clinical Center*

**Sansone Valeria**  
*Clinical and Scientific Director, Full Professor of Neurology, University of Milan*

**Spina Lucia**  
*Specialist in Physical Medicine and Rehabilitation, NeMO Clinical Center*

**Varrenti Marisa**  
*Cardiologist, ASST Grande Ospedale Metropolitano Niguarda*

**Zanolini Alice**  
*Neurologist, NeMO Clinical Center*

## PROGRAM: 21<sup>st</sup> November

- 08:30 - 09:00** Welcome & Introduction:  
DM1 in Italy - How we work  
V. Sansone
- 09:00 - 09:45** DM1 - Diagnosis, Phenotypes & Treatment  
A. Zanolini, C. Ferrari Aggradi
- 09:45 - 10:15** Adults with DM1 - challenges and expectations  
A. Zanolini, C. Ferrari Aggradi, S. Pozzi
- 10:15 - 10:45** Swallowing Function & Nutrition  
V. Sansone, C. Cattaneo
- 10:45 - 11:15** Respiratory Management  
E. Roma, M. Croci, A.Cima
- 11:15 - 11:30** BREAK
- 11.30 - 12.00** Cardiac management  
M.Varrenti
- 12.00 - 12.30** Cognitive and behavioral issues  
V. Sansone, C. Ferrari Aggradi, G. Colacicco
- 12.30 - 13.00** Which models of care?  
All attendees
- 13.00 - 14.00** LUNCH
- 14.00 - 16.00** Meet the TEAM  
Roles & Responsibilities - & the patients Groups split into 3 (30 mins each session)  
Groups exchange as feasible
- Group 1: Early Care lab (E. Gotti, S. Pozzi, E. Bazzoni)  
Group 2: Respiratory lab and swallowing (E. Roma, M. Croci, A. Cima, C. Cattaneo)  
Group 3: Rehabilitation programs (L. Spina, C. Agliuzzo)
- 16.00 - 16:30** BREAK
- 16.30 - 17.00** Interactive and Discussions from Milan group and from attendees  
Nemo Team and delegates
- 17.00 - 17:30** Wrap up Day 1  
V. Sansone

## PROGRAM: 22<sup>nd</sup> November

- 08:30 - 08:45** Welcome & Introduction: Day 2  
V. Sansone
- 08:45 - 09:15** Patient Transitions - Adolescent to Adult our Experience  
E. Albamonte, S. Pozzi
- 09:15 - 09:45** Cognitive and behavioural issues in peds  
V. Sansone, S. Pozzi
- 09:45 - 10:15** BREAK
- 10:15 - 12:15** Interactive Experience Studies - Delegates
- 10:15 - 11:00 Experience 1: NeMO team  
11:00 - 11:45 Experience 2: Delegates  
11:15 - 12:15 Experience 3: Delegates
- 12:15 - 13:10** Hot Topics: new treatments and expectations; criticalities  
(urinary & sexual problems/pelvic floor; surgeries/palliative care)  
V. Sansone, A. Greco, A.Zanolini, N.Birman
- 13:10 - 14:15** LUNCH
- 14:15 - 14:45** NeMO Tour  
NeMO Team
- 14:45 - 15:15** Regroup - Key Learning Session - future consideration  
(eHealth in DM1)  
V. Sansone, G. Colacicco
- 15:15 - 15:45** Wrap up & Certificates  
V. Sansone