

Myotonic Dystrophy Peer to Peer Program

SCIENTIFIC RATIONALE

DM1 Peer-to-Peer Program

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



Undergoing EACCME accreditation

unrestricted educational grant



Interested participants can register directly through the following link,
providing all requested details:

<https://dm1milan2025.myquadra.it/login>

organizing secretariat

FIRSTCLASS
We Make Things Happen

First Class - Meetings and Conferences
Via Vittoria Colonna, 40
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Myotonic Dystrophy Peer to Peer Program

21st - 22nd November 2025

The NeMO Center - Milan, Italy

Piazza Ospedale Maggiore 3 Blocco Sud, Pad 7, Ala D, piano 2



SCIENTIFIC COORDINATOR:

Valeria Sansone

*The Nemo Clinical Center - Fondazione Serena Onlus
Milano*



Myotonic Dystrophy Peer to Peer Program

FACULTY

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Cardiologist, ASST Grande Ospedale Metropolitano Niguarda,

Zanolini Alice
Neurologist, NeMO Clinical Center

PRELIMINARY PROGRAM

PROGRAM: 21st 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. Aggradi
- 09:45 - 10:15 Adults with DM1 - challenges and expectations
A. Zanolini, C. Aggradi, J. Casiraghi
- 10:15 - 10:45 Swallowing Function & Nutrition
V. Camesasca, 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. 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 5 (30 mins each session)
Groups exchange as feasible
- Group 1: EarlyCare 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: 22nd November

- 08:30 - 08:45 Welcome & Introduction: Day 2
Recap of day 1
V. Sansone
- 08:45 - 09:15 Patient Transitions - Adolescent to Adult our Experience
E. Albamonte, S. Pozzi, I. Giaccompoli
- 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
- Experience 1: NeMO team - 10:15 - 11:00
Experience 2: Delegates - 11:00 - 11:45
Experience 3: Delegates - 11:45 - 12:15
- 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