

eNMD 2021



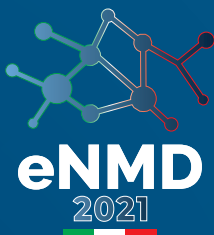
3rd eNMD Congress

E-HEALTH & INNOVATION TO OVERCOME
BARRIERS IN NEUROMUSCULAR DISEASES

29th-30th october 2021
PISA

HYBRID EVENT

**Remote Monitoring:
New solutions for New Avenues
in Neuromuscular Disorders**



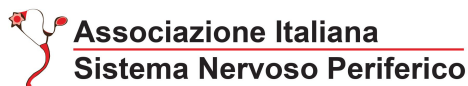
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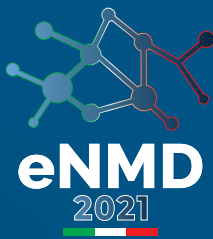
E-HEALTH & INNOVATION TO OVERCOME
BARRIERS IN NEUROMUSCULAR DISEASES

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PRELIMINARY PROGRAM

Under the auspices of:





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3rd eNMD Congress

E-HEALTH & INNOVATION TO OVERCOME
BARRIERS IN NEUROMUSCULAR DISEASES

This 3rd edition of the e-NMD Congress, E-health & Innovation to overcome barriers in Neuromuscular Diseases, follows the previous one, expected to be in Pisa 30-31 October 2020, actually completely virtual at that time. This the reason why we now propose again Pisa for this edition, hopefully in a hybrid form. The main theme chosen for this year focuses on "Remote Monitoring", an emerging theme within the e-health world, now critically figured out from the Covid-19 era and for sure a topic of interest in the wider field of assistive technology & innovation for NMD.

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Preliminary Program

Day 1

12.00 Registration

12.30-13.50 Satellite Symposium: Biotech achievements for development of innovative drugs
(CME non-accredited session)

Chairs: R. Danesi (IT), C. Kornblum (DE)

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12.30 Roche in Neuroscience and rare disease: engaged in the development of drugs and synergistic digital solutions" **A. Ghirardini, (IT)**

12.50 Fine tuning targeted endonucleases: a new gene-editing therapeutic approach strategy in mitochondrial disorders **M. Minczuk (UK)**

13.10 High level customization in the development of Telemonitoring systems in Pompe disease **C. Proietti (IT)**

13.30 MyRealWorld: the app for Myasthenia Gravis patients **R. Mantegazza, (IT)**

13.50-14.15 Break

14.15-14.20 Welcome and Introduction: G. Siciliano (IT), S. Sacconi (FR)

14.20-15.00 Lecture-1: Introducing: G. Mauri (IT), J. Vissing (DK)

How Covid-19 changed the traditional concept of Remote Monitoring: opinions in comparison

- The clinical point of view: a neuromuscular specialist: **G. Comi (IT)**
- The technical point of view: an e-Health scientist: **A. Sciarrone (IT)**

15.00-15.15 Coffee Break

15.15-16.35 Platform Session-1 New strategies to define suitable outcome measures of ADL in NMD
Chairs: T. Mongini (IT), JP Plancon (FR)

15.15 Has Covid-19 pandemic redesigned outcomes and tools for patients needs priorities?
the lesson from transthyretin amyloidosis polyneuropathy **D. Pareyson (IT)**

15.35 Biosensors for exploring conventional and new functional domains **JJ Serrano, (ES)**

15.55 Molecular sensors in Neuromuscular Diseases: myth or reality? **B. Schoser, (DE)**

16.15 Artificial intelligence to optimize strategies for outcome measures selection **M. Bochicchio, (IT)**

16.35-17.35 Free Oral communication session-1

Chairs: T. Klopstock (DE), M. Mancuso (IT)

17.35-18.55 Platform Session-2 New strategies for data capturing
Chairs: T. Evangelista (FR), L. Fanucci (IT)

17.35 Disease registries as source for designing informative outcome measures **A.M. Atalaia, (FR)**

17.55 Everyday quality of life: how to cope needs of patients and caregivers **S. Segovia-Kueny, (FR)**

18.15 Big data for intersection between phenomics and therapeutic pipeline:
future perspectives **H. Lochmuller, (CA)**

18.35 Remote delivery of motor function assessments for clinical care and clinical trials in NMD during COVID-19
global Pandemic **M. James, (UK)**

18.55-19.10 Day closure and remarks

19.10 Welcome Cocktail

Preliminary Program

Day 2

09.00-09.30 Lecture-2: Introducing:

Screenshot of “Proximity Medicine” in EU: the link between Hospital and the Territory **A. Toscano, (IT)**

09.30-10.50 Platform Session-3: Interventional strategies for motor functional restoring

Chairs: *S. Mazzoleni (IT), C. Paradas (ES)*

09.30 Artificial Muscles and Interactive Soft Robotics: recent progress and expectations **R. Riener, (SW)**

09.50 Neuroscience-inspired Soft Robotics Technologies for Prosthetics and Rehabilitation:
Results and Perspectives **A. Bicchi, (IT)**

10.10 Augmented interactions: from rehabilitation to the social inclusion **P. Fedele, (IT)**

10.30 Assistive technologies to promote the inclusion in labour career and
to mitigate occupational stress in NMD patients **T. Duong, (USA)**

10.50-11.05 Coffee Break

11.05-12.05 Free Oral communication session-2

Chairs: *C. Angelini (IT), A. Calvo (IT), P. Carlier (FR)*

12.05-12.35 Lecture-3: Introducing: **M. De Visser (NL)**

Digital Health and Remote Monitoring: ethic and legal issues in EU **L. Vicarioli (IT)**

12.35-13.30 Round Table: The voice of the patient: old and new needs

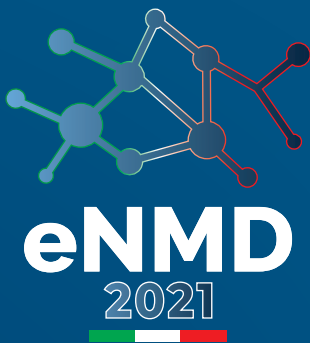
Chairs: *D. Taruscio (IT), D. Mitcov (RO)*

Introduction: would ecologic transition be an added value for AT&I in NMD? (TBD)

Discussants:

*A. Ambrosini (Fondazione Telethon), S. Bellagambi (Uniamo), P. Garzena (CIDP Italia Onlus),
D. Julkowska (EJP RD), L. Ouillade (AFM-Telethon), V. Pace (gli Equilibristi HIBM),
C. Bruno (UILDM), Christian Lunetta (AISLA)*

Conclusive remarks



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BARRIERS IN NEUROMUSCULAR DISEASES

Congress Venue
Grand Hotel Continental
Via Belvedere, 26, 56128 Tirrenia (PI)

Congress web site:
<https://www.miologia.org/eNMD2021/>

Registration and abstract submission information are available on the congress web site

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