

# eNMD 2021



## 3<sup>rd</sup> eNMD Congress

E-HEALTH & INNOVATION TO OVERCOME  
BARRIERS IN NEUROMUSCULAR DISEASES

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29<sup>th</sup>-30<sup>th</sup> october 2021  
PISA

HYBRID EVENT

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





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BARRIERS IN NEUROMUSCULAR DISEASES

29<sup>th</sup>-30<sup>th</sup>  
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PISA

under the patronage of



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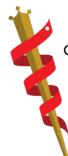
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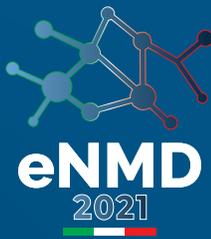
ORDINE  
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European  
Reference  
Network  
for rare or low prevalence  
complex diseases

Network  
Neuromuscular  
Diseases (ERN EURO-NMD)





29<sup>th</sup>-30<sup>th</sup>  
October 2021  
PISA

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This 3<sup>rd</sup> edition of the e-NMD Congress, E-health & Innovation to overcome barriers in Neuromuscular Diseases, follows the previous one completely virtual which it was initially thought to be in Pisa, therefore this is the reason why to propose again the same location, in a hybrid form. The main theme chosen for this edition focuses on "Remote Monitoring", an actual aspect that recently emerged among e-health and its configurations also due to the Covid-19 era. In any case this topic we hope to be of interest in the wider field of assistive technology innovation for NMD.

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Gabriele Siciliano (IT)  
Sabrina Sacconi (FR)  
John Vissing (DK)

### Local Organizing Committee

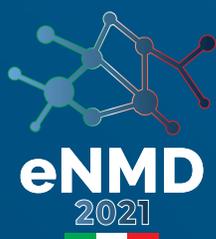
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Giulia Ricci  
Francesca Torri  
Cecilia Carlesi  
Michelangelo Mancuso

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Antonio Toscano, Messina  
Luca Vicarioli, Turin  
John Vissing, Copenhagen (DK)



## 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)*

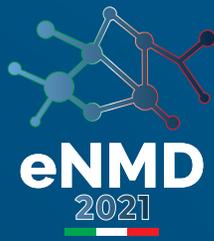
#### 16.35-17.35 Free Oral communication session-1

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

Technological innovation in neurorehabilitation process using wearable sensor system  
*Mehrnaz Hamedani (Genoa)*

The InGene 2.0 technological platform: software and hardware solutions meet the clinicians in NMD  
*Alessandro Tonacci (Pisa)*

Neuromuscular ultrasound longitudinal changes as marker for disease progression in amyotrophic lateral sclerosis/motor neuron disease: is it time to use quantitative muscle ultrasound monitoring?  
*Paolo Bongioanni (Pisa)*



## Program

### Day 1

Myotonic Dystrophy Type 1 and the Serious Game X-Torp: Results of a Feasibility Study  
*Lorenza Santoni (Pisa)*

Unlocking the potential of deep learning and cloud computing to assess the evolution  
of dysarthria in patients with Amyotrophic Lateral Sclerosis  
*Lucia Migliorelli (Ancona)*

#### 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)*

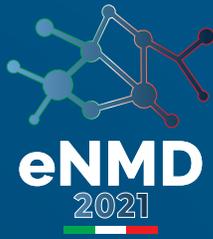
**17.55** Everyday quality of life: how to cope needs of patients and caregivers *S. Segovia-Kueny, (FR)*

**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**



## Program

### Day 2

**09.00-09.30 Lecture-2:** Introducing: *C. Angelini (IT)*

Screenshot of "Proximity Medicine" in EU: the link between Hospital and 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: A. Calvo (IT), P. Carlier (FR)*

Design Healthcare Innovation: Fostering Patient-driven innovation - *Stefano Maffei*

Assessing the usability of a wearable device in telemonitoring neuromuscular patients - *Marco Salivetto (Milan)*

Robotic assessment with artificial intelligence in the evaluation of ALS disease progression  
*Marco Salivetto (Milan)*

Exploiting Artificial Intelligence for speech rehabilitation in dysarthric patients - *Marco Marini (Pisa)*

Set up of a gaze-enabled device in an adult SMA type 1 patient: a tool to overcome  
isolation and to monitor residual distal motor function - *Edoardo Malfatti (Paris)*

**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)*

#### **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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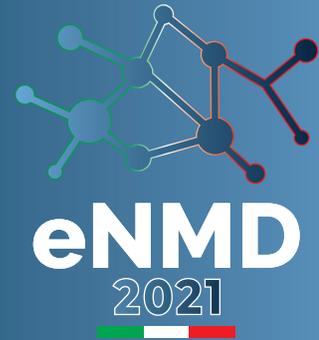
## Congress Venue

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

## Congress web site:

<https://www.miologia.org/eNMD2021/>

Official language: english



Italian CME credits: 5,6

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PLATINUM

**SANOFI GENZYME**

GOLD



OTHERS

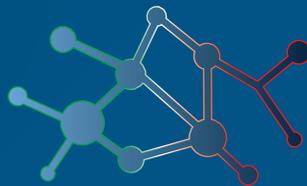


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Viale Italia, 173 - 57128 Livorno  
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[elena.falciola@fclassevents.com](mailto:elena.falciola@fclassevents.com)



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2021



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