

# eNMD 2021



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

E-HEALTH & INNOVATION TO OVERCOME  
BARRIERS IN NEUROMUSCULAR DISEASES

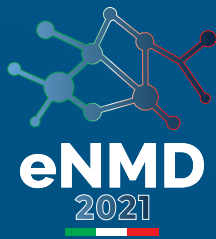
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29<sup>th</sup>-30<sup>th</sup> october 2021  
PISA

HYBRID EVENT

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





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This 3<sup>rd</sup> 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.

### Scientific Committee

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

### Local Organizing Committee

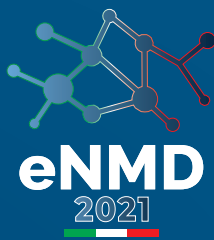
Erika Schirinzi  
Giulia Ricci  
Francesca Torri  
Cecilia Carlesi  
Michelangelo Mancuso

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Gabriele Siciliano, Pisa  
Domenica Taruscio, Roma  
Antonio Toscano, Messina  
Peter Van der Berg, Brussels (BE)  
John Vissing, Copenhagen (DK)



## 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)

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

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

**13.10** High level customization in the development of Telemonitoring systems in Pompe disease **G. Parenti, (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 point of view of neuromuscular specialist: **G. Comi (IT)**
- The point of view of a company CMO: **J. Hallock (USA)**

#### 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** One year experience: has Covid-19 pandemia redesigned outcomes and tools for patients needs priorities?  
**MA Rubio, (ES)**

**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)**

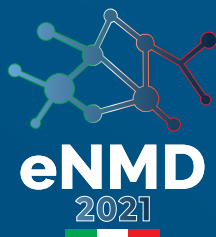
**17.55** Everyday quality of life: how to cope needs of patients and caregivers **S. Segovia-Kueny, (FR)**

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

**18.35** Home therapy and clinical follow-up solutions for clinical trial management **J. Diaz Manera, (UK)**

#### 18.55-19.10 Day closure and remarks

#### 19.10 Welcome Cocktail



## Preliminary Program

### Day 2

**09.00-09.30 Lecture-2:** Introducing: *P. Van den Berg (BE)*

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** Sensory neuroscience: Sensory based approach to help in restoring chronic disabilities  
(haptic, vision, e-textiles) *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 *M. Bertrand, (FR)*

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

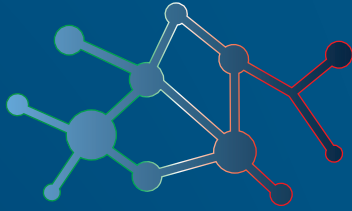
*Chairs: Taruscio (IT), D. Mitcov (RO)*

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

**Participants:**

*A. Ambrosini (Telethon-Italia), S. Bellagambi (Uniamo), P. Garzena (CIDP Italia Onlus),  
D. Julkowska (EJP RD), L. Ouillade (AFM-Telethon), V. Pace (gli Equilibristi HIBM),  
S. Pedroni (UILDm), Fulvia Massimelli (AISLA)*

**Conclusive remarks**



**eNMD**  
2021

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**Congress web site:**

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

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

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Organizing Secretariat / CME Provider



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