



eNMD
2023

4th

ENMD

Congress

IV. CONGRESS IN E-HEALTH & INNOVATION
TO OVERCOME BARRIERS IN NEUROMUSCULAR
DISEASES

2nd - 4th november 2023

MUNICH

Digital biomarkers and digital therapies:
New solutions for New Avenues
in Neuromuscular Disorders



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Scientific Committee

Benedikt Schoser (DE)
Sabrina Sacconi (FR)
Gabriele Siciliano (IT)

Local organizing Committee

Federica Montagnese

eNMD Advisory Board

Gabriele Siciliano, (IT)
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Corrado Angelini (IT)
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Valeria Sansone (IT)
Benedikt Schoser (DE)
Antonio Toscano (IT)

Invited Speakers

Corrado Angelini (IT)
António Marques Atalaia (FR)
Jan Baumbach (DE)
Nicolas Dubuisson (BE)
Teresinha Evangelista (FR)
Lorenzo Guizzaro (EMA)
Alaa Hamed (USA)
Jean-Yves Hogrel (FR)
Sophie Lehnerer (DE)
Hanns Lochmüller (CA)
Marco Lorenzi (IT)
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Angelo Schenone (IT)
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Eric Schott (DE)
Gabriele Siciliano (IT)
Maike Stein (DE)
Barbara Tettenborn (CH)
Antonio Toscano (IT)
John Vissing (DK)
Arthur Miller (UK)
Paola Alberti (IT)
Stephan Wenninger (DE)
Tiffany House (USA)



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DAY 1 - 2nd of November 2023

11:00 Registration

12:00 - 13:30 **pre-Industry Satellite Symposium / apps and tools for NMD**

Chair: Benedikt Schoser (DE)

12.30 - 13.00 New digital tools for patients with myotonia: where do we stand? *Prof. Yan Pereon*

13.00 - 13.30 Patient app: Tiny steps towards a more active lifestyle in the realm
of neuromuscular diseases (*speakers TBD*) *Alexion*

14:00 Welcome and Introduction: *Benedikt Schoser (DE)*

Topic 1 **Digital monitoring and databases**

Chairs: *Gabriele Siciliano (IT)*; *Benedikt Schoser (DE)*

14:15 Disease monitoring in 2030 - *Angelo Schenone (IT)*

14:45 Data sharing on web-based platforms - how to overcome classic hurdles? - *Jan Baumbach (DE)*

15:15 Treatabome database: a variant-based decision-making aid for treating rare
and neuromuscular disorders - *António Marques Atalaia (FR)*

15:45 Industry demands in clinical trials - *Alaa Hamed (USA)*

16:15 End of the session

16:15 - 16:45 **Coffee break**

Topic 2 **Digital biomarkers**

Chairs: *Valeria Sansone (IT)*, *Stephan Wenninger (DE)*

16:45 How to develop digital biomarkers - *Martin Daumer (DE)*

17:15 **Oral Communications**

17:15 - 17:30 **Oral 1** | *Qi Tang*

Sensorless Computer Vision-Based Motor Function Assessment:
Revolutionizing Patient Evaluation with AI and Videos Taken by Smart Devices

17:30 - 17:45 **Oral 2** | *Ghobad Maleki*

Objective Monitoring of Facioscapulohumeral Dystrophy During Clinical Trials using a Smartphone
Application and Wearables: Observational Study

17:45 - 18:00 **Oral 3** | *Erick Kruitwagen*

Evaluation of the nation-wide implementation of telemonitoring in the care for patients with ALS:
ALS Home Monitoring and Coaching

18:00 - 18:15 **Oral 4** | *Rosella Tupler*

Computational Models for new Patients Stratification Strategies of Neuromuscular Disorders:
a new strategy to tackle hereditary neuromuscular disorders

18:15 End of the session

18:15 Evening Keynote lecture

Generative AI Creates Art and Literature But is it the Real Thing? *Arthur Miller (UK)*

19:00 Network evening

DAY 2 - 3rd of November 2023

08:00 - 9:00 Industry Breakfast Satellite Symposiums by Argenx

Innovations to overcome barriers in myasthenia gravis

09:15 Introduction of Day 2 - *Benedikt Schoser (DE)*

Topic 3 Device Development

Chairs: *Jean-Yves Hogrel (FR)*, *Katrin Hahn (DE)*

09:20 Neuromuscular devices - what do we have in place already? - *Jean-Yves Hogrel (FR)*

09:50 Oral Communications

09:50 - 10:05 Oral 1 | *Baetrice Labella (IT)*

Exploring the role of Mobile Health Technologies in detecting subtle motor impairment in paucisymptomatic Late-onset Pompe Disease: a preliminary study

10:05 - 10:20 Oral 2 | *Elisa Panero (IT)*

Wearable devices for the biomechanical investigation of DMD during the 6MWT: preliminary results

10:20 - 10:35 Oral 3 | *Alessandro Tonacci (IT)*

InGene 2.0: How a technological platform supports the clinicians in the diagnosis and treatment of neuromuscular disorders

10:35 - 10:50 Oral 4 | *Eric Voorn (NL)*

Usability of a mobile health application to support home-based aerobic exercise in neuromuscular diseases

10:50 - 11:00 Discussion

11:00 End of the session

11:00 - 11:30 Coffee break

Topic 4 Remote monitoring and telemedicine

Chairs: *Antonio Toscano (IT)*, *Teresinha Evangelista (FR)*

11:30 Remote monitoring - an unmet need for patients and clinicians - *Gabriele Siciliano (IT)*

12:00 Digital monitoring of myasthenia gravis - *Sophie Lehnerer (DE)*

12:30 Data management and security in the light of an insurance company - *Markus Schlobohm (DE) TK Germany*

13:00 End of the session

Lunch

13:15 - 14:15 Industry Lunch Satellite Symposia

Harnessing Digital Technology to Optimise Patient Care in the Long-Term Management of NMD

13:30 - 13:35 Welcome and introductions

13:35 - 13:40 Introduction to patient-centric disease management - *S. Dando*

13:40 - 13:50 Co-creation of digital content by HCPs and patients/caregivers - *K. Amana*

13:50 - 14:00 Case study: An example of how digital technology has supported patients with their physiotherapy - *S. Dando*

14:00 - 14:15: How can we harness digital technologies to optimise patient management? - *S. Dando, K. Amana*

14:15 - 14:30: Q&A

Workshops, Speed-dating, and e-Poster pitches

14:30 - 15:30 Workshop 1 - Digital platforms for data sharing and decentralized mining

Jan Baumbach (DE) group Computational system biology University Hamburg

15:30 - 16:00 Coffee break

16:00 - 16:45 Workshop 2 - e-Education in eNMD and beyond

Chair: Corrado Angelini (IT)

16:00 EAN educational platform - *Barbara Tettenborn (CH)*

16:20 PNS educational platform - *Paola Alberti (IT)*

16:40 - 16:45 Discussion

16:45 - 17:30 e-poster pitches

Chair: Hanns Lochmüller (CA)

17:30 - 18:30 Speed dating - poster session - networking sessions:

Chairs: Eric Schott (DE), Benedikt Schoser (DE), Hans Lochmüller (CA)

DAY 3 - 4th of November 2023

08:30 - 09:30 Industry Breakfast Satellite Symposiums - TBD BY Biogen

09:30 Introduction of Day 3 - Benedikt Schoser (DE)

Topic 5 Technical therapeutics

Chairs: Federica Montagnese (DE), Nicolas Dubuisson (BE)

09:45 Technical solutions for mobility and rehabilitation - *Olivier Lambergcy (CH)*

10:15 End of session

Coffee break

Topic 6 eNMD in the real world

Chairs: John Vissing (DK), Nicole Voet (NL)

10:45 eNMD in the real world setting - what do we have in hand and what do we need? - *Marco Lorenzi (IT)*

11:15 eHealth and innovation in NMD: the gold standard or red tape? - *Nicole Voet (NL)*

11:45 Digital integrated care solutions for the neuromuscular community - presence and future
Andreas Ziegler (DE)

12:15 Patients voices on e-health - *Tiffany House (USA)*

12:45 Congress wrap-up and farewell - Benedikt Schoser (GE)

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