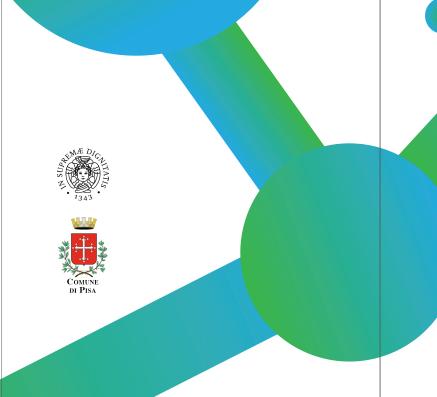
# 20<sup>TH</sup> - 21<sup>ST</sup> MARCH 2020

E-HEALTH & INNOVATION TO OVERCOME BARRIERS IN NEUROMUSCULAR DISEASES – ENMD

## SCIENTIFIC COMMITTEE

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



### Congress Web site: www.miologia.org/eNMD2020/

Registration will be valid only upon receipt of written confirmation by the Organizing secretariat.

## Organizing Secretariat CME Provider



Viale Italia 173 - 57127 Livorno Ph. +39 0586 849811 Fax: +39 0586 349920

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20<sup>TH</sup> - 21<sup>ST</sup>

MARCH 2020

# E-HEALTH & INNOVATION

TO OVERCOME BARRIERS
IN NEUROMUSCULAR
DISEASES – ENMD

#### **ARSENALI REPUBBLICANI**

VIA BONANNO PISANO, 2 56126 PISA PI



The Congress is purposed to address, in the frame of a patient-focused assistive technology, various relevant issues related to digital health in Neuromuscular Diseases, from diagnosis to treatment, patient monitoring and his real life world.

The eNMD Congress has been accredited for Italian CME

#### N° OF CREDITS: 9,1

#### The Congress is addressed to:

Neurologists, Physiatrists and Physiotherapists. Myopathologists, Neuroradiologists, BioEngineers, Molecular Biologists, BioInformatics, Bio and Pharmaceutical Technology Researchers

Under the auspices of:

AIM, ASNP, ERN Euro-NMD, EAN, RD-Connect, Eurordis, EJPRD, Telethon-I, AFM-Telethon NMDs Patient Charities and Associations, UniPI, Ministry pf Health.

### SCIENTIFIC COMMITTEE

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

# LOCAL ORGANIZING COMMITTEE

Giulia Ricci Erika Schirinzi Costanza Simoncini Michelangelo Mancuso

### ADVISORY SCIENTIFIC COMMITTEE

Corrado Angelini (IT)
Teresinha Evangelista (FR)
Hans Lochmuller (CA)
Jordie Diaz-Manera (ES)
Benedikt Schoser (DE)
Sandrine Segovia-Kueny (FR)
Domenica Taruscio (IT)

# 20 MARCH

**13:30** Registration

#### 14:00-15:30

Satellite Symposium:

Molecular biotechnology for drug development and innovative therapeutic strategies in Neuromuscular Diseases (NMDs). Discussant: C. Blandizzi, C. Martini

Ksenija Gorni - Drug development challenges: the lesson of Risbiplan in SMA treatment. Claudia Travesana - RNAi as a new approach for therapy in neuromuscular genetic rare diseases.

Valentina Zipoli - The therapeuthic approach with antisense oligonucletide to NMD. Chiara Proietti - High level customization: Telemonitoring systems on Pompe disease and development perspectives.

#### 15:30-15:50

Greetings and introduction:

Where tradition meets innovation in NMDs.
G. Siciliano, T. Evangelista, M. Marra

#### 15:50

**Lecture 1** Artificial intelligence in NMDs': why it can help and

which the different approaches to get it done.

J. Diaz-Manera

#### 16:20 Coffee break

#### 16:40

Lecture 2 Telemedicine and mobile health: new tools in caring of patients with neuromuscular disorders. P. Scilingo

#### 17:10-18:30

Session 1- Round Table
Assistive technology for
e-Health: EU-exchange
strategies, ethical issues
and the voice of patients.

D. Taruscio, S. Segovia-Kueny

#### 19:00

Welcome reception



# 21 MARCH

#### 8:00-9:00

Starts up and Innovation – An overview on the biomedical engineering and its uses in Neuromuscolar Medicine Chair: G. Siciliano, S. Maffei, S. Segovia-Kueny

#### 9:00-10:50

Session 2 - Diagnosis: Big data for Biological Systems, Digital biomarkers, Nerve-Muscle Imaging, Tissue Pathology.

Sacconi S.- FACE-NMD: diagnosis of NMDs by facial recognition Bendham D. - Muscle MRI segmentation techniques for NMD: advantages for diagnosis and followup.

Knieling F. - Light in-sound out: non invasive molecular imaging in NMDs. Bochicchio M. - Early detection of Rare Diseases: a web-based system for monitoring maternal and fetal health. Nigro V. - Big data for genomic approach to the diagnosis of NMDs. Conte R. - InGene - A suite of tools for a better diagnosis in NMDs.

#### 10:50

Coffee break

#### 11:10-13:00

Session 3 - Therapies: Digital outcome measures in clinical trials, Telemedicine and treatment Effectiveness Monitoring, e-Registries.

Vissing J. - How can we improve the reliability of the "6 min walking test" in monitoring NMD patients
Messina S. - Digital outcome measures in DMD and SMA patients: perspectives and new challenges
Annoussamy M. - Results of the use of Actimyo, a digital biomarker platform for NMDs

Ricci G, Billeci L. - Wearable technologies for the assessment of fatigue for clinical trials in NMDx

#### CORE PROGRAM: A journey along the patient real life

Boentert M, Spießhöfer J. - Follow-up of respiratory muscle involvement, treatment indication and monitoring of home ventilatory support in patients with NMD Plancon J.-P. - Real life evidence: gathering data to better understand patients living with immune-mediated

peripheral neuropathies: the

NEUROQUALI project

#### 13:00

Lunch

#### 14:00-15:00

Pitch session 1 - Domotic systems for enhancing autonomy and QoL in NMD - V. Sansone, P. Santantonio

#### 15:00-16:50

Session 4- Rehabilitation: Biosensors and Connecting devices. Robotics

Frisoli A. - Technical advancements for assistive robotics in Neuromuscular Subjects Chisari C - New technologies for assessment and rehabilitation in NMDs: do we need a consensus statement?

Hamedani M. - Technological innovation in neurorehabilitation process using wearable sensor system

Tognetti A. - Wearable device and methods for the assessment of gait parameters in daily life D'Angelo G.- USEFUL: User-centered

Assistive System for Arm Functions in NMDs

Mahmoud Alheou - P-T- AMADEUS robotic system rehabilitation in DM1 patients 16.50- coffee break

#### 17:00-18:00

**Pitch session 2 -** What's new on e-Health in NMD: visionary or reality? M. Mancuso, E. Pegoraro

#### 18.00

Conclusive remarks