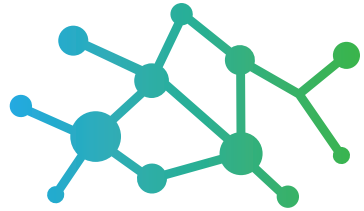


WAITING FOR 2021  
E-NMD CONGRESS



**eNMD**  
2020

**E-HEALTH &  
INNOVATION**

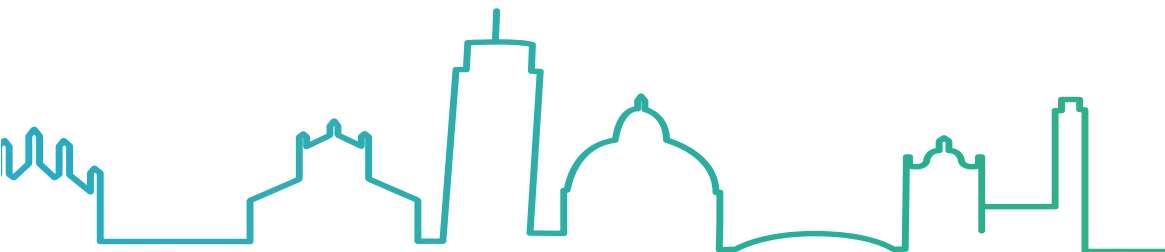
**30<sup>TH</sup> - 31<sup>ST</sup>**

OCTOBER 2020

DIGITAL EDITION  
VIRTUAL EVENT

TO OVERCOME BARRIERS  
IN NEUROMUSCULAR  
DISEASES - ENMD

**A POINT AND WRAP MOMENTUM**



This second edition of the e-NMD 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, bringing, at European-scaled level, scientists with different backgrounds, clinicians, biotech, bioengineers and bioinformatics.

Dear Colleagues, Dear Friends,

after the slow motion game of the isolation due to Covid-19 pandemia, where our practice has been noticeably upset, everyone has had, between widely spaced appointments, some time to reflect: "the future is cloudy and uncertain...surely the way we practice medicine is going to change, and for a long while....": who has never thought this?... Sure, "panta rei", cogitate Eraclito (5th Century BC) so long ago by now, and the spirit of the scientist can only be animated by the call of challenges. The aim to outline innovative solutions in diagnosis, treatment and care of the patient with a neuromuscular disease has been and, even more so now, continues to be an important milestone along the road to improve management of these diseases.

It is time to come back after cancellation of the original e-NMD 2020 Congress that had to be held in Pisa, 20-21 march 2020., to "gather a momentum" for wishing you to share knowledge and new ideas, with the perspective to hopefully organize a live event next year, 2021.

It is in this view that we propose our missed appointment in a new dress, with the hope that this concise meeting could represent a useful opportunity to realize what has been changed for Covid pandemia but, at the same time, what this has given us to be learned for the future.

Point and wrap!



**Congress Web site:**  
[enmd.myquadra.it](http://enmd.myquadra.it)

**Organizing Secretariat**



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

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.



**Under the auspices of:**

AIM, ASNP, RD-Connect, Eurordis, EJPRD, Telethon-I, AFM-Telethon NMDs  
Patient Charities and Associations, UniPI, Ministry of Health

**The Congress is addressed to:**

Neurologists, Psychiatrists and Physiotherapists. Myopathologists,  
Neuroradiologists, BioEngineers, Molecular Biologists, Bioinformatics, Bio and  
Pharmaceutical Technology Researchers

**SCIENTIFIC  
COMMITTEE**

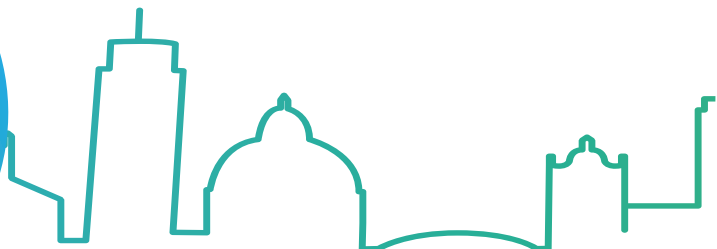
Gabriele Siciliano, (IT)  
Sabrina Sacconi (FR)  
John Vissing (DK)

**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)  
Antonio Toscano (IT)

**LOCAL  
ORGANIZING  
COMMITTEE**

Giulia Ricci  
Erika Schirinzi  
Costanza Simoncini  
Michelangelo Mancuso





## 08:45-09:00

Live Greetings and introduction  
(G. Siciliano, IT; S. Sacconi, FR,  
M. Marra, IT)

## 09:00-09:30

### Lecture 1 introducing: G. Siciliano (IT)

Covid in review: featuring  
e-Health for the management  
of quarantine  
(D. Pedreschi, IT)

## 09:30-10.40

### INTERACTIVE SESSION 1

"Everything's got a moral, if  
only you can find it": Hints for  
Diagnosis in Neuromuscular  
disorders

Chairs: G. Siciliano(IT),  
T. Evangelista (FR)

## 09:30-09:50

Concept, set up and application  
of disease registry: ERN experience  
(Peter-Bram't Hoen, NL)

## 09:50-10:10

Digital imaging biomarkers  
in neuromuscular disorders  
(D. Bendahan, FR)

## 10:10-10:30

Home Telemonitoring of Covid-19  
patients: the experience of the  
Tel.Tec.CoViD19 project  
of the North-West Tuscany ASL  
(L. Fanucci, IT)

## 10:30-11:05

Discussion

## 11:05-12:05

Meet the Experts and Discuss  
on NMD Diseases: New biotech  
approaches for Diagnosis  
and Treatment

Chairs: R. Horvath (UK),  
D. Pareyson (IT)

Pompe Disease

Expert: F. Montagnese, DE

MELAS disease

Expert: M. Mancuso, IT

Hereditary amyloid TTR  
polyneuropathy

Expert: G. Siciliano, IT

Spinal Muscular Atrophy

Expert: E. Mercuri, IT

## 12:05-13:25

### INTERACTIVE SESSION 2

Novel challenges  
for outcoming clinical trials

Chairs: (T. Mongini, IT;  
S. Sacconi, FR)

## 12:05-12:25

Before and after tomorrow:  
how Covid pandemia renews  
the need of outcome measures  
in NMD

(J-P Plancon FR)

## 12.25-12.45

Wearable devices and sensors  
to improve monitoring and data  
collection: power and pitfalls  
(L. Billeci, IT)

## 12.45-13.05

Optimizing data output  
from 6MWT  
(J. Vissing, DK)

## 13.05-13.25

Succesfull clinical trial in NMD:  
what can we learn from  
telemedicine  
(B. Schoser, DE)

## 13.25-13.40

Discussion

## 13.40-14.10

Lunch

## 14.10-14.40

Meet the Experts and Discuss  
on NMD Diseases:  
New biotech approaches  
for Diagnosis and Treatment  
(Chairs: R. Horvath, UK,  
D. Pareyson IT)

## 14.40-15.10

### Lecture 2 introducing: G. Siciliano (IT)

Tele-Health: repurposing  
challenges to improve  
the neuromuscular disease care:  
what we learnt from lock-down.  
(E.P. Scilingo, IT)

Discussion:

Experts:

F. Montagnese, DE,  
M. Mancuso, IT,  
G. Siciliano, IT,  
E. Mercuri, IT

## 15.10-15.40

### Lecture 3 introducing: V. Nigro (IT)

NMD gene discovery using  
European data infrastructure  
(H. Lochmuller, CA, E)

## 15.40-15.50

Lectures questions and answers,  
and sessions remarks  
(Chair: V. Sansone, IT  
M.J. Molnar, HU)



**31** SATURDAY  
**OCTOBER**

**09:00-09:30**

**Lecture 4 introducing**

C. Angelini (IT)

I Functional priorities and patient oriented outcomes: the add value for clinical research (S. Segovia-Kueny, F)

**09:30-10:45**

**INTERACTIVE SESSION 3**

Restorative hints for the post-Covid restating: how to design the fit

(chairs: E. Pegoraro, IT; P. Santantonio, IT)

**09:30-9:50**

Evolving the priorities for assistive robotics in NMD: clinical perspective in post-Covid era

(A. Frisoli, IT)

**09:50-10:10**

Muscle remodelling after lock-down: is it irreversible or not?

(C. Chisari, IT)

**10:10 - 10:30**

Artificial intelligence to redefine clinical caring : a perspective view

(J. Diaz-Manera, UK)

**10:30 - 10:45**

Discussion

**10:45-11:00**

Break

**11:00-12:00**

**Round table**

frontline reports of emergent critical issues after Covid: perspective strategies for their management

(chairs: L. Ouillade, F; D. Taruscio, I)

Introduction: Overview on clinicians perception of consequences of COVID-19 outbreak on neuromuscular diseases in Europe (S. Sacconi, FR)

Participants:

A. Ambrosini (Telethon-I),

S. Bellagambi (Uniamo),

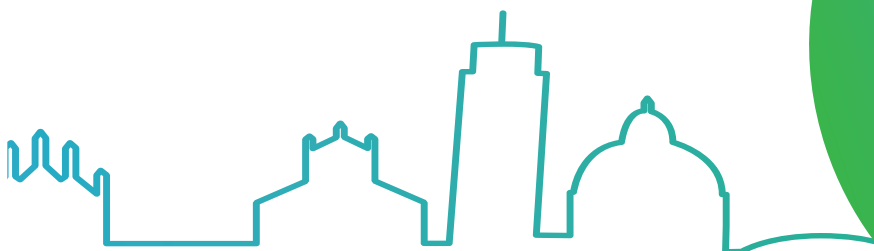
F. Bologna (Deputy Italian Republic),

P. Garzena (EPODIN),

V. Pace (gli Equilibristi HIBM)

**12:00-12:20**

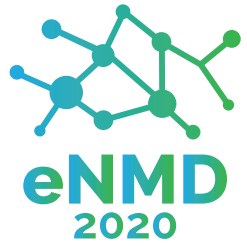
Conclusive remarks



30<sup>TH</sup> - 31<sup>ST</sup>

OCTOBER 2020

DIGITAL EDITION



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R. Horvath  
amyloid TTR polyneu