

ANNUAL ERN EURO-NMD BOARD MEETING



**European
Reference
Network**
for rare or low prevalence
complex diseases

Network
Neuromuscular
Diseases (ERN EURO-NMD)



The European Reference Network for Rare Neuromuscular Diseases Euro-NMD
welcomes you on January, 24th & 25th, 2022
to the **Annual Euro-NMD Board Meeting**, held online

MONDAY, January 24th

ERN Euro-NMD Board meeting – Day 1

15.00-15.10	Welcome <i>(Teresinha Evangelista)</i>
15.10-15.20	Introduction of the new members <i>(Teresinha Evangelista)</i>
15.20-16.15	EURO-NMD Registry <i>Overview (Antonio Atalaia) 10'</i> <i>Technical (Adrian Tassoni, Dagmar Jäger)</i> <i>FAIRification (Peter-Bram 't Hoen, Nawel Van Lin)</i> <i>Legal (Carla D'Angelo)10'</i>
16.15 – 16.30	Coffee Break
16.30-16.45	Guidelines <i>(Antonio Atalaia)</i>
16.45-17.15	Education <i>Overview (Teresinha Evangelista)</i> <i>Future programme (Jean-Philippe Plançon)</i>

	<i>Training mobility (Heike Pascal)</i>
17.15-17.30	Monitoring / Compliance <i>(Heike Pascal)</i>
17.30-18.00	CPMS <i>(Antonio Atalaia, Elisabeth Avidi)</i>
18.00-18.10	Photo Call

TUESDAY, January 25th

ERN Euro-NMD Board meeting – Day 2

15.00-15.15	Inter-ERNs Working Groups <i>(Holm Grässner)</i>
15.15-15.30	Care and Trial Site Registry (CTSR) <i>(Sunil Rogers)</i>
15.30-15.45	SCREEN4CARE <i>(Alessandra Ferlini)</i>
15.45-16.00	S4C Newborn screening clinical implications in NMD's <i>(Jan Kirschner)</i>
16.00-16.15	Coffee break
16.15-16.30	PAB accomplishments and expectations. Interaction with EURORDIS <i>(François Lamy)</i>
16.30-17.30	EURO-NMD Working Groups: Results and prospects <i>(Working Group Chairs)</i> <i>Approx. 7 minutes presentation per WG</i>
17.30-17.40	Discussion /questions
17.40-18.10	Future of the ERN - End of the meeting <i>(Teresinha Evangelista)</i>
18.10-18.15	Photo Call