



# European Reference Network

for rare or low prevalence complex diseases

 **Network**  
Neuromuscular Diseases (ERN EURO-NMD)

The European Reference Network for Rare Neuromuscular Diseases  
welcomes you on February 2<sup>nd</sup> & 3<sup>rd</sup>, 2023 to the

## 6<sup>th</sup> EURO-NMD Annual Meeting

held at the Centro Hospitalar Universitário do Porto, Portugal  
Main Auditorium, rua da Restauração



Hospital de Santo António

**Upon invitation only on Wednesday, February 1<sup>st</sup> :**

### The Meetings before the Annual Meeting

Registry Steering Committee (upon invitation only)	Feb. 1st, room 1 at 09:00
Executive Committee (upon invitation only)	Feb. 1st, room 1 at 17:45

## Thursday, February 2<sup>nd</sup> 2023

### PARALLEL EURO-NMD WORK GROUP MEETINGS (registration required)

	Main Auditorium	Room 1	Room 2	Room 3
8.30-10.15	Neuromuscular Pathology <i>Montse Olivé</i>	Neurophysiology <i>Camiel Verhamme &amp; Peter van den Bergh</i>	Multi-disciplinary Rehab' by <i>Marianne Nordstrøm</i>	

10.15-10.45 COFFEE BREAK and registration (ground floor)

<b>Main Auditorium</b> <b>HANDS-ON WORKSHOP on the REGISTRY HUB</b> (all audiences, registration required)				
10.45-12.45	<b>Hands-on workshop Registry Hub</b> <i>by Dagmar Jäger and Adrian Tassoni</i>			
12.45-13.45 LUNCH				
<b>Main Auditorium</b> <b>EURO-NMD Annual Meeting DAY 1</b> <b>“New therapies in NMD”</b>				
<b>DAY 1</b> <i>Chairpersons: Manuela A. Santos &amp; Teresa Coelho</i>				
13.45-14.00	<b>Welcome note by section chief Dra. Isabel dos Santos</b> <i>M. A. Santos, T. Coelho and T. Evangelista</i>			
14.00-14.40	<b>New therapies in Rare Muscle diseases</b> <i>by Marianne de Visser (Amsterdam)</i>			
14.40-15.20	<b>New therapies in Peripheral Nerve diseases</b> <i>by Davide Pareyson (Istituto Besta, Milan)</i>			
15.20-16.00	<b>New therapies in Mitochondrial diseases</b> <i>by Cornelia Kornblum (Bonn)/ Michelangelo Mancuso (Pisa)</i>			
16.00-16.15 Coffee Break				
<b>DAY 1</b> <i>Chairpersons: Hanns Lochmüller &amp; Janbernd Kirschner</i>				
16.15-17.00	<b>New therapies in Neuromuscular Junction disorders</b> <i>by Hanns Lochmüller (Freiburg, DE), guest: Anthony Behin (Paris)</i>			
17.00-17.45	<b>New therapies in Motor Neuron diseases (SMA)</b> <i>by Janbernd Kirschner (Freiburg, Germany)</i>			
<b>PARALLEL EURO-NMD WORK GROUP MEETINGS</b> (registration required)				
	Main Auditorium	Room 1	Room 2	Room 3
17.45-19.30	<b>Genetics</b> <i>Alessandra Ferlini</i>	<b>Neuromuscular Junction</b> <i>Hanns Lochmüller</i>	<b>Mitochondrial diseases</b> <i>C. Kornblum &amp; M. Mancuso</i>	<b>Patient Advisory Board</b> <i>François Lamy</i>
20.00	<b>Bus-pick-up in front of the Main Auditorium for the restaurant</b>			
20.30	<b>Networking Dinner</b> ( <i>registration required</i> ) Restaurante <b>Casa Da Música</b> - Av. da Boavista 604-610, 7 <sup>th</sup> floor			

## Friday, February 3rd, 2023

### PARALLEL EURO-NMD WORK GROUP MEETINGS (registration required)

	Main Auditorium	Room 1	Room 2	Room 3
8.30-10.30	<b>Imaging (starts 9h !)</b> <i>Pierre Carlier</i>	<b>Peripheral Nerve</b> <i>Daive Pareyson</i>		
<b>10.30-10.45 Coffee Break</b>				
<b>Main Auditorium</b> <b>ERN ANNUAL MEETING Day 2</b> <b>“New therapies in NMD”</b>				
<b>DAY 2</b> <i>Chairpersons: Davide Pareyson, Teresinha Evangelista</i>				
10.45-11.05	<b>aTTR Amyloidosis from clinics to treatment</b> <i>by Teresa Coelho (Porto)</i> 15' talk, 5' Q&A			
11.05-11.25	<b>Education Board: InterERN Post-graduate Curriculum</b> <i>by M. de Visser &amp; J.-Ph. Plançon (Amsterdam &amp; Paris)</i> 15' talk, 5' Q&A			
11.25-11.45	<b>News from the Patient Advisory board</b> <i>by François Lamy (Paris)</i> 15' talk, 5' Q&A			
11.45-12.05	<b>Clinical Trial Site Registry (CTSR)</b> <i>By Sunil Rodger (Newcastle, Freiburg)</i> 15' talk, 5' Q&A			
12.05-12.55	<b>5 case examples</b> 5' presentation + 5' discussion by <i>Fernanda Fortunato (Ferrara) &amp; Francesca Torri (Pisa)</i>			
<b>12.55-13.45 LUNCH</b>				
<b>DAY 2</b> <i>Chairpersons: Bjarne Udd &amp; Hanns Lochmüller</i>				
13.45-14.05	<b>ERKreg &amp; ERICA</b> <i>by Franz Schäfer (Heidelberg)</i> 15' talk, 5' Q&A			
14.05-14.25	<b>Omics &amp; NGS methodology</b> <i>by Alessandra Ferlini (Ferrara)</i> 15' talk, 5' Q&A			
14.25-15.25	<b>6 case examples</b> 5' presentation + 5' discussion by <i>Sabine Rudnik (Innsbruck), Kristin Orstavik (Oslo), Maike Dohrn (Aachen), Wolfgang Müller-Felber, Aleksandra Nadaj-Pakleva</i>			
<b>15.25-15.45 Coffee break &amp; Photo Call</b>				
15.45	<b>Board Meeting</b>			

15.45-16.00	<b>Achievements by Teresinha Evangelista</b> 15' talk, Q&A 10'
16.00-17.00	<b>New grants by Teresinha Evangelista &amp; Joao da Sousa</b> 40' talk, Q&A 10'
17.00-17.40	<b>5- year's Evaluation and new CPMS by Joao da Sousa</b> 30' talk, Q&A 10'
17.40-18.00	<b>Next Meetings &amp; AOB, by Teresinha Evangelista</b> 20' talk, Q&A 10'
18.00	<b>End of meeting, farewell</b>



View of Porto and the river Douro

**WE ARE LOOKING FORWARD TO SEE YOU IN PORTO!**

the ERN EURO-NMD Coordination team