



**SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA**
Azienda Unità Sanitaria Locale di Ferrara



**Università
degli Studi
di Ferrara**

The European Reference Network for Rare Neuro-muscular Diseases Euro-NMD welcomes you on November 6th, 7th & 8th, 2019 to the University Hospital Cona in Ferrara, Italy
Azienda Ospedaliero Universitaria di Ferrara

Wednesday, Novembre 6 th					
14.30-17.30 SATELLITE MEETING GENETIC TESTING with EHSG					Aula Magna
14.30-15.00	Introduction, objectives of the WS <i>Prof. Alessandra Ferlini (Ferrara, Italy)</i>				
15.00-15.30	Gene variant annotation approaches <i>Prof. Maurizio Genuardi (Rome, Italy)</i>				
15.30-16.00	Whole Genome Sequencing Diagnostic Translation <i>Hans Scheffer (Nijmegen, The Netherlands)</i>				
16.00-16.30 Coffee break					
16.30-17.00	« FSHD from epigenetic mechanisms to therapy » <i>Dr. Julie Dumonceaux (London, UK)</i>				
17.00-17.30	Ethical issues in genetic testing <i>Angus Clarke (UK)</i>				
PARALLEL MEETINGS					
	Aula Magna Cap. 312 people	Room 1 Cap. 49 people	Room 2 Cap. 70 people	Room 7 Cap. 70 people	Room 8 Cap. 49 people
17.30-19.00		Research <i>Hanns Lochmüller</i>	TBA	Mitochondrial Diseases <i>Rita Horvath</i>	
20.00 Speaker's Dinner <i>invitation only</i>					

Thursday, November 7 th					
PARALLEL MEETINGS					
	Aula Magna Cap. 312 p	Room 1 Cap. 49 people	Room 2 Cap. 70 people	Room 7 Cap. 70 people	Room 8 Cap. 49 people
09.00-10.30	CPMS session <i>Chloe</i>	Muscle <i>Antonio Toscano</i>	Imaging <i>Pierre Carlier</i>	Neurophysiology <i>Camiel Verhamme</i>	Education <i>Andoni Urtizberea</i>
10.30-11.00 Coffee break					
11.00-16.00 ERN ANNUAL MEETING I					Aula Magna
11.00-11.15	Aula Magna Welcome <i>Alessandra Ferlini/Teresinha Evangelista/ Professor Patrizio Bianchi</i> (Emilia Romagna Region Assessor for the Coordination of European Policies on Development, Education, Vocational Training, University, Research and Employment)				
11.15-11.45	Ramblings in myology: My first 60 years <i>Victor Dubowitz</i>				
11.45-13.00	Aula Magna Newborn Screening (Patients point of view) <i>François Lamy (Paris, France)</i> Pilot Newborn screening example (SMA) <i>Eduardo Tizzano (Barcelona, Spain)</i> German experience on screening more than 250.000 new-borns for SMA <i>Astrid Blaschek (Munich, Germany)</i>				
13.00-14.00 LUNCH					
14.00-14.30	WGS in the genetics diagnostic lab <i>Hans Scheffer</i>				
14.30-15.00	eNMD aims & meeting report <i>Gabriele Siciliano (Pisa, Italy)</i>				
15.00-15.30	2 Case reports – 10 min. each + 5 min. discussion <i>Carmen Paradas & Guido Primiano</i>				
15.30-16.00 Coffee break					
16.00-18.00 BOARD MEETING					Aula Magna
18.00 -19.30 ERN EXECUTIVE COMMITTEE MEETING					Aula Magna
20.30 Social dinner for all attendees in Ferrara (Estense Duke Castle)					

Friday, November 8 th					
09.00 -11.00 ERN ANNUAL MEETING II					Aula Magna
09.00-09.45	Solve-RD & what we can learn from other ERN's <i>Holm Grässner (Tübingen, Germany)</i>				
09.45-10.15	NMD-related Projects (EJP-RD) <i>Dr. Eleonora Passeri</i>				
10.15-11.00	3 Case reports - 10 min. each + 5 min. discussion				
11.00	end of the meeting				
11.00-11.30 Coffee break					
PARALLEL MEETINGS					
	Aula Magna Cap. 312 p	Room 1 Cap. 49 people	Room 2 Cap. 70 people	Room 7 Cap. 70 people	Room 8 Cap. 49 people
11.30-13.00	Pathology <i>Bjarne Udd</i>	PAB <i>François Lamy</i>	Peripheral Nerve <i>D. Pareyson</i>	Genetics <i>Alessandra Ferlini</i>	Neuromuscular Junction <i>H. Lochmüller</i>