

4th ERICA General Assembly & ERN Research Conference

11- 13 December 2024 (Udine, Italy)

preliminary programme: **Wednesday, December 11th 2024**

hosted by: UUH / MetabERN

DAY 1	
13:30 - 14:00	Registration & Coffee
Conference Opening	
Setting the Scene for ERN, RD Research across	
14:00 – 14:10	Welcome By <i>Maurizio Scarpa</i> and <i>Alberto Pereira</i>
14:10 – 14:30	Key Note Speaker By <i>pending</i>
14:30 – 14:40	Key achievements from ERICA Chaired by <i>Alberto Pereira</i> (ERICA Coordinator)
Work Packages sessions (WP2-WP6) WP-leads à 20min (15min+5min Questions)	
14:40 – 15:00	WP2 'Data Collection, Integration and Sharing' By <i>Franz Schaefer</i> and <i>Eduardo Lopez Granados</i>
15:00 – 15:20	WP3 'Patient Centered Research' By <i>Mar Mañú Pereira</i> and <i>Ana Rath</i>
15:20 – 15:40	WP4 'Clinical Trial Support' By <i>Luca Sangiorgi</i> and <i>Ralf-Dieter Hilgers</i>
15:40 – 16:00	WP5 'Translation and Innovation' By <i>Ruth Ladenstein</i> and <i>Anton Ussi</i>
16:00 – 16:30	Coffee break
16:30 – 16:50	WP6 'Integration, Outreach & Dissemination' By <i>Ana Rath</i> , <i>Alberto Pereira</i> and <i>Maurizio Scarpa</i>
16:50 – 17:10	ERN Research: the ERICA Legacy By <i>H Le Borgne</i> (tbc)
17:10– 17:30	Conclusions & Future Perspectives
17:30 – 18:00	Poster pitches à 3 min
18:00 – 19:00	Poster Presentations & Networking reception
19:00	End DAY 1
20:00 – 22:00	Faculty Dinner

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DAY 2	
ERN Research	
8:30 – 9:00	Gathering & Coffee
Session 1: Diagnostic Research (Data Readiness, Genome re-analysis research pipeline, Genomic innovation to shorten time to diagnosis)	
9:00 – 9:15	Plenary: PI SolveRD By <i>Holm Graessner</i> (tbc)
9:15 – 9:30	Oral presentation by (à 15 min)
9:30 – 9:45	Oral presentation by (à 15 min)
9:45 – 10:00	Oral presentation by (à 15 min)
Session 2: Outcome Research (Real World Data, Clinical Outcome Assessment)	
10:00 – 10:15	Using primary healthcare data for clinical research: Directions and Barriers By <i>Franz Schäfer</i>
10:15 – 10:30	Oral presentation by (à 15 min)
10:30 – 10:45	Oral presentation by (à 15 min)
10:45 – 11:00	Oral presentation by (à 15 min)
11:00 – 11:30	Coffee break
Session 3: Innovative Therapies (Advanced Therapeutic Medicinal Products , N-of-few approach)	
11:30 – 11:45	A roadmap to tailored genetic interventions in patients with neurodegenerative disorders By <i>Annemieke Aartsma-Rus</i> (tbc)
11:45 – 12:00	Oral presentation by (à 15 min)
12:00 – 12:15	Oral presentation by (à 15 min)
12:15 – 12:30	Oral presentation by (à 15 min)
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	DAY 2 (continued)
	Session 4: Clinical Trials (Drug Trials, inc. nr of few clinical trials; Non-Pharmacological interventions)
12:30 – 12:50	(PLUTO Program- research in forgotten disorders) By <i>Diego Ardigo</i> , Chiesi, IRDiRC (tbc)
12:50 – 13:10	EMA ACT-EU (Accelerate Clinical Trials in EU) By <i>Ana Zanoletty</i> (tbc)
13:10 – 13:30	C4C By <i>Mark Turner</i> (tbc)
13:30 – 14:30	Lunch
	Session 5: AI in RD Research
14:30 – 15:30	Oxford Debate – Does AI work for RD? Pro's and Con's <i>Ruth Ladenstein</i> casus(Primage project on Neuroblastoma) vs <i>Maurizio Scarpa</i> (algorithms for syntomic feature detection)
	Panel discussion and Key messages Including panellist from UNIUD and European Commission
15:30 – 16:00	Coffee break
16:00 – 17:30	Innovation Workshop
17:30	End DAY 2
19:00 – 22:00	ERN Research Party Social Programme/Dinner including Abstract Award Ceremony

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DAY 3	
Future of the ERN Research	
8:30 – 9:00	Gathering & Coffee
8:30 – 9:00	Building together the ERN Research Roadmap ERN Research strategy alignment
9:15 – 9:45	Panel discussion on corporate identity of ERN Research With ERDERA Moderated by <i>Franz Schäfer, Maurizio Scarpa and Alberto Pereira</i>
Alignment of ERDERA & Jardin & Together4RD	
9:45 – 10:00	Research funding opportunities within ERDERA By <i>Alberto Pereira</i>
10:00 – 10:20	The role of the National Mirror Groups - NMGs By <i>Sonja van Weely (tbc)</i>
10:20 – 10:40	Together4RD Industry & ERN Cooperation By <i>Mathieu Boudes, Sheela Upadhyaya and Vicky Hedley (tbc)</i>
10:40 – 11:10	Coffee break
11:10 – 11:30	Success stories from PPPs Realised, other IHI Projects by <i>Dieter Hilgers and Magda Ghlebus</i>
11:30 – 12:00	Panel discussion
12:00 – 12:15	Take home messages and final words
12:15 – 13:15	Goodbye lunch