European Reference Network
for rare or low prevalence complex diseases
Network Neurological Diseases (ERN-RND)

PROGRAMME

Venue: Ospedale Pediatrico Bambino Gesù, Auditorium, Viale Ferdinando Baldelli, 38

Thursday 8 October 2026

TIME (CET)	TOPIC	SPEAKER
13:00	Opportunity to meet between 13:00 and 15:00 **(internal projects)**	
15:00	**Welcome Coffee**	
15:30	**Welcoming** Words	Holm Graessner University Hospital Tübingen
15:35	**Board Meeting**	Holm Graessner and the coordination team University Hospital Tübingen
18:30	**Guided tour of the Basilica Papale di San Paolo (Papal Basilica of Saint Paul Outside the Walls)**	

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Friday 9 October 2026

TIME (CET)	**TOPIC**	**SPEAKER**
08:30	**Welcome, Setting the Scene**	Holm Graessner, Ludger Schöls, Enrico Bertini
09:00	**2 Disease Group Meetings in Parallel** • **Dystonia, NBIA and Paroxysmal disorders** • **Leukodystrophies**	
10:30	**Coffee Break**	
11:00	**Disease Group Meeting** • **HD and chorea**	
12:30	**Group Photo** **Lunch**	
13:15	**Poster Session** on the current ERN-RND activities: DG and WG projects, funded projects, ePAG activities, core activities	
14:15	**ePAG Presentation**	Lori Renna Linton
14:30	**2 Disease Group Meetings in Parallel** • **Ataxia and HSP** • **FTD**	
16:00	**Coffee Break**	
16:30	**Working Group Meeting** • **Neurorehabilitation WG**	
18:00	**Wrap-ups of ERN-RND Activities** 5-minute Wrap-up for each DG WG, Wrap-up Entire Day	
19:00	**Poster session 2 with drinks and finger food**	

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Saturday 10 October 2026 - Scientific Symposium "Registries for RND"

Session 1: Framework for RND Registries

TIME (CET)	TOPIC	SPEAKER
08:00	Welcome and overview of **ERN-RND activities**	Holm Graessner and Ludger Schöls
08:05	---------- **KEYNOTE** ---------- Why Registries Matter for Rare Neurological Diseases: **from Natural History to Trial Readiness**	**Thomas Klockgether**, German Centre for Neurodegenerative Diseases (DZNE), University Bonn, Germany
08:35	**Framework for Multistakeholder Patient Registries** in the Field of Rare Neurological Diseases	**Nicole Wolf**, Amsterdam University Medical Center, Netherlands
08:55	**Patient Perspective:** What should registries deliver for patients and families?	**Mary Kearney**, FARA Ireland (online)
09:05	**Flash talks (5 min max): ERN-RND local registry initiatives**	
09:25	**Coffee Break**	

Session 2: Registry Examples in ERN-RND

TIME (CET)	TOPIC	SPEAKER
09:50	**ERN-RND use case**	**Holm Graessner,** University Hospital Tübingen, Germany
10:05	**TreatHSP** Natural History and Outcome Validation Platform	**Rebecca Schüle**, University Hospital Heidelberg, Germany
10:25	**The French MSA registry**	**David Bendetowicz**, University Hospital Bordeaux, France
10:45	**NKX2-1 registry: Building an International Disease Registry** in a Very Rare Disorder	**Dario Ortigoza**, Sant Joan de Déu Hospital, Barcelona, Spain
11:05	**Panel Discussion**	**Thomas Klockgether, Nicole Wolf, Rebecca Schüle, Dario Ortigoza**
11:30	**Coffee/Lunch Break**	

Session 3: Regulatory and Methodological Perspectives

TIME (CET)	TOPIC	SPEAKER
12:00	**Registry Qualification and Regulatory Expectations for Rare Disease Evidence Generation**	**Kelly Plueschke**, European Medicines Agency
12:25	Natural History Studies as **Historical Control Data in Trials**	**Ralf Reilmann**, George-Huntington-Institute, Technology-Park Münster, Germany
12:50	**Q&A and Closing remarks**	
13:00	***End of event***	