



PROGRAMME

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 University Hospital Tübingen
18:00	Guided tour of the Basilica Papale di San Paolo	

Friday 9 October 2026

TIME (CET)	TOPIC	SPEAKER
08:30	Welcome, Setting the Scene	Holm Graessner, Ludger Schöls, Rome representative
09:00	2 Disease Group Meetings in Parallel - Dystonia, NBIA and Paroxysmal disorders - Leukodystrophies	
10:30	Coffee Break	
11:00	2 Disease Group Meetings in Parallel - HD and chorea - Atypical Parkinsonian Syndromes	
12:30	Group Photo Lunch	
13:15	Poster Session Data access committee (only for DAC members)	
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	2 Disease Group Meetings in Parallel - Paediatric Issues - Neurorehabilitation	
18:00	Wrap-ups of ERN-RND Activities 5-minute Wrap-up for each DG WG, Wrap-up Entire Day	
19:30	Dinner	

Saturday 10 October 2026 - Scientific Symposium “Registries for RND”

Session 1: Framework for RND Registries

TIME (CET)	TOPIC	SPEAKER
08:00	Welcome Coffee	
08:15	Welcome and overview of ERN-RND activities	Holm Graessner / Ludger Schöls / symposium chairs
08:25	----- 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
08:45	Framework for Multistakeholder Patient Registries in the Field of Rare Neurological Diseases	Nicole Wolf , Amsterdam UMC - Amsterdam University Medical Center, Netherlands
09:05	Patient Perspective: What should registries deliver for patients and families?	Mary Kearney ,
09:15	Flash talks (5 min max): ERN-RND local registry initiatives	
09:35	Coffee Break	

Session 2: Registry Examples in ERN-RND

TIME (CET)	TOPIC	SPEAKER
10:00	ERN-RND use case	Christina Vossler-Wolf , University Hospital Tübingen, Germany
10:15	TreatHSP Natural History and Outcome Validation Platform	Rebecca Schüle , University Hospital Heidelberg, Germany
10:30	The French MSA registry	David Bendetowicz , CHU - Reference Center for Rare Multiple System Atrophy, 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
11:00	Panel Discussion	
11:30	Coffee/Lunch Break Lunch Packs Ready from 12:00	

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
12:30	Natural History Studies as Historical Control Data in Trials	Ralf Reilmann , George-Huntington-Institute, Technology-Park Münster, Germany
12:45	Using Registries in Phase 4 / Post-Authorisation Studies	tbc
13:00	Panel Discussion	
13:30	Closing Remarks and Next Steps	

For further information please contact Sophie Ripp (Sophie.ripp@med.uni-tuebingen.de)

To **register** to the annual meeting click [here](#).