European Reference Network
for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

To register, click here.

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 / Ludger Schöls / symposium chairs
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 UMC - Amsterdam University Medical Center, Netherlands
08:55	**Patient Perspective:** What should registries deliver for patients and families?	**Mary Kearney**, FARA Ireland
09:05	**Flash talks (5 min max): ERN-RND local registry initiatives**	
09:20	**Coffee Break**	

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Session 2: Registry Examples in ERN-RND

TIME (CET)	TOPIC	SPEAKER
09:50	**ERN-RND use case**	**Christina Vossler-Wolf,** 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**, 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
11:05	**Panel Discussion**	
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***	

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