Saturday 10 October 2026 – ERN-RND Scientific Symposium "Registries for RND"
To register, click here.

PROGRAMME

Session 1: Framework for RND Registries

TIME (CET)	TOPIC	SPEAKER
08:30	Welcome and overview of **ERN-RND activities**	Holm Graessner / Ludger Schöls / symposium chairs
08:40	---------- **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
09:00	**Framework for Multistakeholder Patient Registries** in the Field of Rare Neurological Diseases	**Nicole Wolf**, Amsterdam UMC - Amsterdam University Medical Center, Netherlands
09:20	**Patient Perspective:** What should registries deliver for patients and families?	tbc
09:30	**Flash talks (5 min max): ERN-RND local registry initiatives**	
09:50	**Coffee Break**	

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

Session 2: Registry Examples in ERN-RND

TIME (CET)	TOPIC	SPEAKER
10:15	**TreatHSP** Natural History and Outcome Validation Platform	**Rebecca Schüle**, University Hospital Heidelberg, Germany
10:30	**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
11:00	**Panel Discussion**	
11:30	**Coffee 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
12:30	Natural History Studies as **Historical Control Data in Trials**	tbc
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)