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)