



European Reference Network
for rare or low prevalence complex diseases

🌐 **Network**
Neurological Diseases
(ERN-RND)

ANNUAL MEETING

10-11 October, Ljubljana, Slovenia

Venue: Lecture room, University Medical Centre Ljubljana,
Zaloška cesta 7, 1000 Ljubljana, Slovenia

PROGRAMME

October 10th – Day 1

TIME (CEST)	TOPIC	SPEAKER
10:30 – 11:00	Welcome Coffee	
11:00 – 11:05	Welcome	Holm Graessner University Hospital Tübingen
11:05 – 11:30	Overview of ERN-RND	Holm Graessner University Hospital Tübingen
11:30 – 12:00	Optimizing the Patient Journey	ERN-RND Patient Representatives
----- Scientific Symposium: Translation and Innovation -----		
FRAMEWORK		
12:00 – 12:30	European Partnership for Brain Health (online)	Ulrike Busshoff Coordination and support action BrainHealth
12:30 – 13:00	Rare Diseases Regulation	European Medicine Agency (speaker tbc)
13:00 – 13:15	EU login and CPMS Account Creation	Tamara Martin ERN-RND coordination office
13:15 – 14:00	Lunch	
RESOURCES		
14:00 – 14:30	The EJP RD Innovation Management Toolbox and the ERICA Catalogue of Services	Agustín Arasanz Duque Vall d'Hebron Institute of Research
14:30 – 15:00	The Orphan Drug Development Guidebook (ODDG)	Anneliene Jonker IRDIRC
15:00 – 15:30	Affordable Medicine for Rare Diseases (online)	Carla Hollak Amsterdam UMC
15:30 – 16:15	Group Photo and Coffee Break	
RND USE CASES		

16:15 - 16:45	Translational Development of Emrusolmin for the treatment of MSA	Johannes Levin LMU Munich
16:45 - 17:15	Guanabenz (repurposing small molecules) for vanishing white matter (online)	Marjo van der Knaap Amsterdam UMC
17:15 - 17:45	SKYCLARYS , first Therapy to Treat Friedreich's Ataxia	Biogen
17:45 - 18:15	Preclinical and Clinical Data of Lu AF82422 in MSA	Lundbeck
18:15 - 18:30	WRAP-UP DAY 1	
18:30 – 19:00	Registry Data Access Committee Meeting (only for DAC members)	
19:30	Dinner Restavracija Vodnikov Hram, Vodnikov trg 2, 1000 Ljubljana	

October 11th – DAY 2

TIME (CEST)	TOPIC
----- DISEASE GROUPS Parallel Session -----	
08:00 – 09:30	Atypical Parkinsonian Syndromes DG / Leukodystrophies DG / Neurorehabilitation WG
09:30 – 11:00	Ataxia and HSP DG / FTD DG / Pediatric Issues WG
11:00 – 11:30	Coffee Break
11:30 – 13:00	Dystonia, Paroxysmal Disorders and NBIA DG / HD and Chorea DG
13:00 – 14:00	Lunch
----- DG and WG WRAP-UP on Last Years' Activities and New Developments -----	
14:00 – 14:10	Dystonia, NBIA and Paroxysmal Disorders
14:10 – 14:20	Ataxia and HSP
14:20 – 14:30	FTD
14:30 – 14:40	Leukodystrophies
14:40 – 14:50	Chorea and Huntington Disease
14:50 – 15:00	Pediatric Issues
15:00 – 15:10	Atypical Parkinsonian Syndromes
15:10 – 15:30	WRAP-UP DAY 2
15:30 – 15:50	Coffee Break
15:50 – 16:50	Board Meeting