

Network Neurological Diseases (ERN-RND)



**ERN-RND Annual Meeting 2025** 

## **PROGRAMME**

### **Sunday 26 October 2025**

TIME (CET)	TOPIC	SPEAKER
15:00	Welcome coffee	
15:30	Welcoming Words	Holm Graessner University Hospital Tübingen
15:35	Board Meeting	Holm Graessner University Hospital Tübingen
17:30	Data Access Committee	
18:00	Dinner	
19:00	Come Together and Networking	



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# Monday 27 October 2025

TIME (CET)	TOPIC	SPEAKER
08:30	Welcome, Setting the Scene	Holm Graessner, Ludger Schöls, Carla Palleis
09:00	<ul><li>2 DG in Parallel</li><li>Dystonia, NBIA, Parox. Disorders</li><li>Leukodystrophies</li></ul>	
10:30	Coffee break	
11:00	<ul><li>2 DG in Parallel</li><li>HD and Choreas</li><li>Atypical Parkinsonian Syndromes</li></ul>	
12:30	<ul><li> Group Photo</li><li> Lunch</li></ul>	
13:40	Co-Designing Care: The Role of Patient Representatives in ERN-RND	ePAG
14:00	<ul><li>2 DG in Parallel</li><li>Ataxia and HSP</li><li>FTD</li></ul>	
15:30	Coffee break	
16:00	<ul><li>2 WG in Parallel</li><li>Paediatric Issues</li><li>Neurorehabilitation</li></ul>	
17:10	Wrap-ups of ERN-RND Activities 5-minute Wrap-up for each DG WG, Wrap-up Entire Day	
18:00	Dinner	
19:30	Posters & Drinks Current ERN-RND Activities:  DG and WG Projects Funded Projects ePAG Activities Core Activities	



#### **Tuesday 28 October 2025**

Session 1: Cross-border Access to Highly Specialized Therapies for Ultra-Rare Conditions

TIME (CET)	TOPIC	SPEAKER
08:20	Fetal Surgery as an ERN Example	Jan Deprest (ERN ERNICA, Leuven)
08:40	"Just Like Home" Program at Fondazione Telethon for Accessing Gene Therapy	Stefano Zancan (Fondazione Telethon Milan)
09:00	EURORDIS' Lighthouse Concept	Ines Hernando (Eurordis)
09:20	Krabbe Disease Expert Panel	Pascal Martin (Tübingen)
09:40	Panel Discussion	
10:10	Coffee break	

# Session 2: Multidisciplinary Case Discussion for Controlling Access and Ensuring Best Possible Outcome for Highly Specialized Therapies

TIME (CET)	TOPIC	SPEAKER
10:40	<b>Epilepsy</b> Surgery as an EpiCARE Use Case	Alexis Arzimanoglou (ERN EpiCARE, Barcelona)
11:00	<b>Deep Brain Stimulation</b> – Pitch and Live Case Discussion	Martin Reich (Würzburg)
11:30	Metachromatic Leukodystrophy Treatment Eligibility – Pitch and Live Case Discussion	Nicole Wolf (Amsterdam)

#### Session 3: JARDIN - Integration of ERNs into National Healthcare Systems

TIME (CET)	TOPIC	SPEAKER
12:00	Overview and First Results of the JARDIN project	Till Voigtlaender (Vienna)
12:20	National Reference Networks	Holm Graessner (Tübingen)
12:40	Development and Implementation of ERN Care Pathways	Birutė Tumienė (Vilnius)
13:00	National Support of ERN Members	Pavla Doležalová (Prague)
13:20	Panel Discussion	

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