



## 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	



## Monday 27 October 2025

TIME (CET)	TOPIC	SPEAKER
08:30	<b>Welcome, Setting the Scene</b>	Holm Graessner, Ludger Schöls, Carla Palleis
09:00	<b>2 DG in Parallel</b> <ul style="list-style-type: none"><li>• Dystonia, NBIA, Parox. Disorders</li><li>• Leukoencephalopathies (Seminarraum)</li></ul>	
10:30	<b>Coffee break</b>	
11:00	<b>2 DG in Parallel</b> <ul style="list-style-type: none"><li>• HD and Chorea</li><li>• Atypical Parkinsonian Syndromes (Seminarraum)</li></ul>	
12:30	<b>Group Photo</b> <b>Lunch</b>	
13:40	<b>Co-Designing Care: The Role of Patient Representatives in ERN-RND</b>	ePAG
14:00	<b>2 DG in Parallel</b> <ul style="list-style-type: none"><li>• Ataxia and HSP</li><li>• FTD (Seminarraum)</li></ul>	
15:30	<b>Coffee break</b>	
16:00	<b>2 WG in Parallel</b> <ul style="list-style-type: none"><li>• Paediatric Issues</li><li>• Neurorehabilitation (Seminarraum)</li></ul>	
17:10	<b>Wrap-ups of ERN-RND Activities</b> 5-minute Wrap-up for each DG WG, Wrap-up Entire Day	
18:00	<b>Dinner</b>	
19:30	<b>Posters &amp; Drinks</b> Current ERN-RND Activities: <ul style="list-style-type: none"><li>• DG and WG Projects</li><li>• Funded Projects</li><li>• ePAG Activities</li><li>• Core Activities</li></ul>	

## Tuesday 28 October 2025

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

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

### 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 Surgery</b> 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	<b>Metachromatic Leukodystrophy</b> 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 <b>First Results of the JARDIN project</b>	Till Voigtlaender (Vienna)
12:20	<b>National Reference Networks</b>	Holm Graessner (Tübingen)
12:40	Development and Implementation of <b>ERN Care Pathways</b>	Birutė Tumienė (Vilnius)
13:00	<b>National Support of ERN Members</b>	Pavla Doležalová (Prague)
13:20	<b>Panel Discussion</b>	
13:50	<b>End of Event</b> <b>(lunch packs available)</b>	

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