



It will be streamed online - the participation is free, please register [here](#).

PROGRAMME

Tuesday 28 October 2025

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

Chaired by Ines Hernando

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	<i>Coffee break</i>	

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

Chaired by Ludger Schöls

TIME (CET)	TOPIC	SPEAKER
10:40	Epilepsy Surgery as an EpiCARE use case	Alexis Arzimanoglou (ERN EpiCARE, Barcelona)
11:00	Deep brain stimulation – 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

Chaired by Holm Graessner

TIME (CET)	TOPIC	SPEAKER
12:00	Overview and First Results	Till Voigtländer (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)