

Draft Agenda – ERN-Workshop: RARE TOGETHER

Venue Van der Valk Nijmegen-Lent, date: May 8-9, 2023

Day 1 – Exploring the overarching needs in rare diseases.

Time	Session name/Topic	Speaker and Affiliation
10:00 - 10:45	Welcome	
11:00 - 11:45	Common needs in uncommon conditions Where we are coming from and what we need in pediatric rare diseases	Dr. Rosanne Smits, Dr. Chris Verhaak, Amalia Children's Hospital, Radboudumc Nijmegen, NL
11:45 - 12:30	Living with a rare disorder: parent and patient experiences	Dr. Charlotte von der Lippe, Centre for Rare Disorders, Rikshospitalet, Oslo University Hospital, NO
12:30-13:30	Lunch	
13:30 - 14:15	H-Care Developments & Future Proposal	Jessie Dubief, EURORDIS,
14:15 - 15:00	Care coordination for people living with a rare condition	Holly Walton, Department of Applied Health Research, University College London, UK
15:00 - 15:30	Discussion, key insights from Day 1	All participants
15:30 - 15:45	Coffee break + bites	
16:00 - 18:00	Creative activity 'RARE TOGETHER'	All participants
19:00 - 21:00	Live cooking buffet	



Day 2. Interventions and tools for rare diseases

Time	Session name/Topic	Speaker and Affiliation
08:30 - 09:00	Welcome coffee and tea + mini pastry	
	Interventions	
09:00 - 09:45	Pediatric interventions and insights from practice	Aukje Aerts, Amalia Children's Hospital, Radboudumc, Nijmegen, NL
09:45 - 10:30	Family-based intervention programs for children affected by rare disease and their families – research network (CARE-FAM-NET)	Dr. Johannes Boettcher Department of Child and Adolescent Psychiatry, University Medical Center Hamburg-Eppendorf, Hamburg, DE
10:30 - 10:45	Coffee break + bites	
10:45 - 11:30	Clinical experiences	Wendy van Zelst / Wout Feitz / Ivo de Blaauw / TBA
11:30 - 12:30	Patient experiences	TBA
12:30 - 13:30	Lunch	
13:30 - 15:30	First consortium meeting 'Rare Together' <ul style="list-style-type: none"> - Funding opportunities - Future directions Development of theoretical framework - Development of interventions - Consensus statement 	
15:30 - 15:45	Afternoon break	
16:00	Closing	