



Draft Agenda – Workshop RARE TOGETHER WP17

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 & Care for Rare in Radboudumc: Insights and experiences from clinical practice	Dr. Jan Peter Rake, Medical director Amalia Children's Hospital, Nijmegen Prof. dr. Wendy van Zelst Chair Care for Rare, Radboudumc Nijmegen
10.45-11.00	Coffee & tea break	
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, Department of Medical Genetics, Telemark Hospital Trust, Skien, Norway
12:30-13:30	Lunch	
13:30 – 14:15	Care coordination for people living with a rare condition	Dr. Holly Walton, Department of Applied Health Research, University College London, UK
14:15 – 15:00	Psychological support at diagnosis of a rare disease	Dr. Tom Kenny, Director Rare Disease Research Partner, UK
15:00 – 15:15	Coffee break	



15:15 – 16 :00	Discussion and evaluation of day 1	All participants
16 :30 – 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
8:30-9:00	Welcome Coffee and tea	
9:00-9:30	Interventions Pediatric interventions and insights from practice	Aukje Aerts, Psychotherapist, Amalia Children's Hospital, Radboudumc, Nijmegen, NL Prof dr. Ivo de Blaauw Pediatric Surgeon, Amalia Children's Hospital, Radboudumc Nijmegen, NL
9:30-10:30	Interventions for families of children with rare diseases	Prof. Dr. Laura Inhestern (UKE, Hamburg, Germany) and dr. Krister Fjermestad (Oslo University, Norway)
10:30 – 10:45	Coffeebreak + bites	
10:45-11.30	SPIN: development of self-management program in rare disease	Dr. Linda Kwakkenbos, Radboud University, Nijmegen, NL.
11:30-12:15	H-Care Developments & Future Proposal	Dr. Jessie Dubief, EURORDIS. France
12:15 – 13:15	Lunch	
13:15 – 16 :00	First consortium meeting 'Rare Together'	



	<ul style="list-style-type: none"> - Funding opportunities - Future directions Development of theoretical framework - Development of interventions - Consensus statement 	
16:00	Closing	

