

TRANSITION OF CARE WORKSHOP

Friday 17th 08:30 – Saturday 18th 13:30, March 2023

Monasterium PoortAckere, Oude Houtlei 56, Ghent, Belgium

WORKSHOP AIMS

(1) Face-to-face networking event, bringing all stakeholders together, that will result in a plan of action to improve age-appropriate and transitional care in patients with rare liver disease throughout Europe. (2) To reach a consensus on PROMS/PREMS of healthcare transition and to establish a Youth Panel and a cross-ERN framework.

AGENDA

Thursday 16 th March	Monasterium PoortAckere		
17:00 – 18:30 Deicing – meet & greet session for patients Karsten Vanden Wyngaert Michele De Hosson			
Friday 17 th March	Monasterium PoortAckere		
07:30 – 08:15 Breakfast			
08:30 – 09:30 Preparations and patients Karsten Vanden Wyngaert Ena Lindhart	08:30-08:35	Introduction	
	08:35-08:50	Discussion data – Communication 3 topics (1A, 1B, 1C)	
	08:50-09:05	Discussion data - Organizational aspects of transition 3 topics (2A, 2B, 2C)	
	09:05-09:20	Discussion data - Educational needs 3 topics (3A, 3B, 3C)	
	09:20-09:30	Q&A on workshop	
09:30 – 09:45 Break			
09:45 – 10:30 Introduction Ruth De Bruyne	09:45-09:55	Welcome and introduction (goals and methodology of event) <i>Ruth De Bruyne</i>	
	09:55-10:30	State of The Art <i>Anneloes Van Staa</i> <i>Marianne Samyn</i>	
10:30 – 10:50 Break			
10:50 – 12:30 Session 1: Communication Anneloes Van Staa	10:50-11:15	Tools opeigenbenen.nl – <i>Anneloes Van Staa</i> Presentation of obtained data – <i>Ena Lindhart</i>	
	11:15-11:20	Change rooms to break-out sessions	
	11:20-12:30	Topic 1A <i>Ena Lindhart</i>	Topic 1B <i>Mohammed Ali</i>
12:30 – 13:30 Lunch			

13:30 – 15:10 Session 2: Organizational aspects of transition <i>Deirdre Kelly</i>	13:30-13:55	Alternative structures for transition – <i>Michele De Hosson</i> Presentation of obtained data – <i>João Madaleno</i>		
	13:55-14:00	Change rooms to break-out sessions		
	14:00-15:10	Topic 2A <i>José Willemse</i>	Topic 2B <i>Deirdre Kelly</i>	Topic 2C <i>Isabel Goncalves</i>
15:10 – 15:30 Break				
15:30 – 17:10 Session 3: Educational needs <i>Marianne Samyn</i>	15:30-15:55	Taboo – ... Presentation of obtained data – <i>Mohammed Ali</i>		
	15:55-16:00	Change rooms to break-out sessions		
	16:00-17:10	Topic 3A – educational needs caregivers <i>Zoé Mariño</i>	Topic 3B – educational needs patients <i>Panayiota Protopapa</i>	Topic 3C – educational needs parents <i>Ruth De Bruyne</i>
19:00 – 22:00 Social dinner and special activity				
22:00 – ... Constructive night talks				

Saturday 18th March		Monasterium PoortAckere			
07:30 – 08:15 Breakfast					
08:30 – 10:05 Recap Day 1 <i>Deirdre Kelly</i>	08:30-08:35	Introduction <i>Deirdre Kelly</i>		Kick-off meeting Youth Panel <i>Jemma Day</i>	
	08:35-08:45	Session 1 – Communication	Presentation Plan of action		
	08:45-09:05		Feedback and next steps		
	09:05-09:15	Session 2 – Organizational aspects	Presentation Plan of action		
	09:15-09:35		Feedback and next steps		
	09:35-09:45	Session 3 – Educational needs	Presentation Plan of action		
	09:45-10:05		Feedback and next steps		
10:05 – 10:25 Break					
10:25 – 12:25	Group 1 PROMS and PREMS <i>Jo Wray – Eva Goossens</i>		Group 2 Cross-ERN Framework <i>Ruth De Bruyne – Karsten Vanden Wyngaert</i>		Kick-off meeting Youth Panel <i>Jemma Day</i> <i>Anastasia</i>
	10:25-11:25 – state of the art 11:25-11:55 – discussion on important outcomes 11:55-12:25 – consensus on standardized outcome measures		10:25-10:35 – Introduction and aims 10:35-11:05 – Presentation of current and future projects 11:05-11:25 – Legal/political framing 11:25-12:25 – conceptualization of cross-ERN framework		
12:25 – 12:35 Closing statements <i>Deirdre Kelly - Ruth De Bruyne</i>					
12:30 – 13:30 lunch					
13:30 – 15:30 Reserve	Group 1 PROMS and PREMS <i>Jo Wray – Eva Goossens</i>		Group 2 Cross-ERN Framework <i>Ruth De Bruyne – Karsten Vanden Wyngaert</i>		Kick-off meeting Youth Panel <i>Jemma Day</i>