

MetabERN Annual Board MEETING

9-10 April 2018

Lindner Congress Hotel, Frankfurt

Frankfurt, Germany

9 April 2018 Program		Parallel Session	
9:00-9:40	Opening remarks: aim of the meeting and network vision <i>Maurizio Scarpa</i>		
9:40-10:10	White Paper <i>Daniela Negri</i>		
10:10-10:40	The patients' role in MetabERN: the first year of work together <i>Anne Hugon TBC</i>		
10:40-10:45	Discussion		
10:45-11:00	Coffee Break		
11:00-11:20	The U-IMD Registry <i>Stefan Kölker</i>		
11.20-11.40	Cooperation between U-IMD and the ERKNet registry <i>Franz Schäfer</i>		
11.40-12.00	The EU RD Registration tools <i>Holger Storf</i>		
12.00-13.10	Discussion		
13:10-14:00	Lunch		
14:00-14:30	The CPMS <i>Herman Brand (EC)</i>		
Follow 30 mins Presentations for each WP: What has been done and what needs to be completed (5 mins) Encountered problems (5 mins) Plans for the Second Year (5) mins) discussion and inputs from the Subnetworks & Patient Organizations (15 mins)			
14:30-15:00	Work Package 5: Virtual Counseling Framework <i>Klaus Mohnike & Terry Derks</i>		
15:00-15:30	Work Package 1: Coordination Presentation of the result of the Satisfaction Survey MetabERN <i>Maurizio Scarpa</i> Discussion on Advisory Board <i>Daniela Negri & Karen Schober</i>		
15:30-16:00	Work Package 4: Guidelines and Care Pathways and Standardisation <i>Athanasia Ziagaki & Carlo Dionisi</i>		

16:00-16:30	Work Package 3: Evaluation <i>Viktor Kozich</i>		
16:30-17:00	Coffee break		
17:00-17:30	Work Package 8: Continuity of Care <i>Maurizio Scarpa & Yngve Thomas Blikrud</i>	16.45-18.30	Parallel Session: U-IMD Registry <i>Stefan Kölker and the U-IMD Team</i>
17.30-18:00	Work Package 2: Dissemination <i>Mireia Del Toro</i>		
18:00-18:30	Work Package 7: Capacity Building & Training <i>Nadia Belmatoug</i>		
18:30-19:00	Discussion and Wrap-up <i>Maurizio Scarpa</i>		
	Dinner		

10 April 2018	
8:30-9:30	Work Package 6: Research, Translational Activities and Clinical Trials <i>Maurizio Scarpa & Cinzia Bellettato</i> Work Package 6: Report on advancements in selected fields of IMD research <i>Jean Michel Heard</i>
	<i>Coffee</i>
09:45-12:00	7 parallel breakout sessions of the disease sub-networks
12:00-13:00	Sub-networks reports in plenary (8-10 minutes per group)
13:00-14:00	Lunch
14:00-14:30	MetabERN involvement in EU projects <i>Maurizio Scarpa</i>
14:30-15:30	Sustainability of the Network/Stakeholder Meeting/establishment of <i>MetabERN grant office</i> <i>Maurizio Scarpa & Ans van der Ploeg</i>
15:30-15:45	Results Satisfaction Survey <i>Maurizio Scarpa & Corine van Lingen</i>
15:45-16:00	Getting ready for the annual IAB Assessment <i>Maurizio Scarpa</i>
16:00-16:30	Discussion and wrap up
17:00	End of meeting