



## MetabERN BOARD MEETING 4-6 April 2019 Frankfurt, Germany

Thursday 10.00-14.00		
11.00-13.15	Pre-meeting of Subnetwork (SNW) Coordinators, Work Package (WP) Leaders and Single Point of Contacts (SPOCs)	Moderators: Each WP + SNW-leader, Maurizio Scarpa
13.15-14.00	Lunch	
Thursday 4 April 14.00-19.00		
14.00-16.00	METABERN General opening Update on important issues (20 mins each) <ul style="list-style-type: none"> <li>• Highlights of the 3-5 year plan (</li> <li>• Patient Involvement: Governance structure</li> <li>• CPMS</li> <li>• Monitoring</li> </ul> Q&A/Discussion	Moderators: <ul style="list-style-type: none"> <li>• Maurizio Scarpa</li> <li>• Lut deBaere/Anne Hugon</li> <li>• Terry Derks</li> <li>• Viktor Kozich</li> </ul>
16.00-16.30	Coffee Break	
16.30-18.30/19.00	Update-U-IMD registry  Q&A/Discussion	Moderator: Stefan Kölker
18.30/19.00	Dinner	
Friday 5 April 8.30-19.00		
8.30-10.30	WPs Parallel sessions: Discussing deliverables Year 3-5  WP2& WP7 (stay in the main meeting room) WP3 and WP5 grouped together WP4 and WP9 grouped together WP6 and WP8 grouped together	Moderators: WP-leaders
10.30-11.00	Coffee Break	
11.00-12.30	Plenary discussion of cross-cutting topics of general interest (30 mins each): <ul style="list-style-type: none"> <li>• New-Born Screening</li> <li>• Transition</li> <li>• Education/dissemination</li> <li>• E-learning</li> </ul>	Moderators: Maurizio Scarpa/Trine Tangeraas Graziella Cefalo/Christina Lampe Nadia Belmatoug/Mireia del Toro Terry Derks
12.30-13.30	Lunch break	
14.00-16.00	Feedback and reporting back to plenary session from the WP and discussion with POs Representatives	
16.00-19.00	<b>Parallel session on U-IMD</b>	Moderator: Stefan Kölker
	Parallel session Patient Board (all patient organisations and representatives present)	Moderators: Lut deBaere/ Anne Hugon/Simon Bond

	<b>Parallel session MetabERN Clinical Pathway Recommendations/Guidelines Meeting</b> 16:00-16:10 Presentation "Why CRP/GL?" 16:10-17.00 Interactive tour of the CPR/Platform 17:00-18.30 Workshop "Step-by-step Guide to set up your CPR/GL" Setting up a CPR either as one by its own or as part of the development of GL 18.30-18.45 Questions & Answers 18,45-19.00 Setting of deadlines & Closing remarks	<i>Ursula Plöckinger</i> <i>Ursula Plöckinger</i>  <i>Athanasia Ziagaki, Ursula Plöckinger, Corine van Lingen</i>  <i>All</i>  <i>Maurizio Scarpa</i>
<b>Saturday 6 April 8.00-13.00</b>		
8.00-10.30	SNW Parallel sessions <ul style="list-style-type: none"> <li>• AOA</li> <li>• LSD</li> <li>• C-FAO</li> <li>• PD/NOMS/PMMD/CDG (small separate groups to be organized in the main meeting rooms)</li> </ul>	<i>Moderators: SNW-leaders</i>
10.30-11.00	Coffee break	
11.00-13.00	Reporting back from the SNW-Parallel sessions	<i>Moderators: SNW-leaders</i>
13.30-14.00	Lunch	
<b>End of the meeting</b>		

\* During the meeting Cinzia and Corine will be available to help you with your questions about the Clinical Patient Management System (CPMS)