



Minutes taken by LS & BM

Minutes of UEMS Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases (MJC RUD) board meeting

Date: October 20, 2018; 13:15-14:00			Protocol No 3/2018
Place: Thon Hotel, Brussels			
Attendees: Vassilios Papalois (special guest) <i>UEMS Secretary General</i> Bela Melegh <i>President, Section of Medical Genetics</i> Liesbeth Siderius <i>acting Secretary, Section of Pediatrics</i> Alexandre Bisdorff <i>Section of Neurology</i> Serdar Ceylander <i>Turkish NMA</i> Maeve Durkan <i>Section of Endocrinology</i> Marc Hermans <i>Section of Psychiatry</i> Norbert Mulleneisen <i>Section of Allergy</i> Apologies: Marisa Dias Nursel Celik Basaran Daniela Karall			

	Points	Discussion	Decisions	
1	Opening	Meeting is open at 13:15, with delay.	Due to the delay, the Agenda points 2 & 8 to be discussed mainly electronically, points 4-7 to be discussed together verbatim	BM
2	Agenda point 3	<p>ENETS contacted the UEMS for collaborate in EU exam.</p> <p>A confcall was organized (04.07.18) with A. Pascher, A. Frilling, VP, Lise Carratala, BM. ETR materials were sent along to ENETS partners by LC.</p> <p>IT expert involvement to the MJC RUD suggested</p>	<p>MoU needs to be prepared soon (before their meeting in 30.11.18.)</p> <p>VP will send available MoU forms to BM;</p> <p>a Position (white) paper will be considered on “undiagnosed” topic.</p> <p>MJC RUD will find partners for collaboration via email contact of Sections</p>	<p>VP</p> <p>BM</p> <p>to be named</p> <p>BM</p>
3	Agenda points 4-7	<p>ETR for "Rare Diseases" European Board of Rare Diseases</p> <p>ETR for “Rare adult solid cancers”</p> <p>European Board of Rare adult solid cancers”</p>	<p>All points were considered merit for further development.</p> <p>Call will be circulated amongst Section to identify experts who interested to join; working group(s) will be created</p>	BM
4	Agenda point 8	Joint Action in Rare Cancers (JARC)	Was incorporated in part into the previous point, slides will be circulated later.	BM
5	Agenda point 9	Election postponed (low number of attendees, lack of proxies)	LS remains acting secretary	VP, BM
6	AOB	MD & NM MJC RUD membership application was approved	Monetary support via EU grants will be considered	