



European Academy of Paediatrics  
Paediatric Section of U.E.M.S (European Union of Medical Specialists)



Provisional Agenda Rare Disease WG  
(EAP, UEMS Section of Paediatrics)  
Spring meeting

Faro, Friday May 12th 2017  
WG Rare Diseases 9.00- 10.30 **HALL Gemini 2**  
Vilamoura, Algarve, Portugal

1. Attendance and apologies
2. Minutes Winter Meeting Brussels 2016
3. Report UEMS Multidisciplinary Joint Committee Rare and Undiagnosed Diseases  
*Liesbeth Siderius (15 min)*
4. Report on the 3<sup>rd</sup> European Reference Network Conference in Vilnius, March 9<sup>th</sup> 2017  
*Liesbeth Siderius (15 min)*
5. "Rare Diseases Care Organization in Portugal"  
*Maria do Céu Machado,*  
*Vice President of the National Council for Health and*  
*Member of the National Bioethical and Life Sciences Council in Portugal and*  
*Vice President of the European Federation of Medical Academies*  
*(30 minutes)*
6. General discussion activities in the field of rare diseases
  - new activities
  - how to proceed?

LS March 25<sup>th</sup> 2017