



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)

Winter meeting

Brussels, Friday December 2th 2016 16  
WG Rare Diseases 11.00 - 12.30 **Room 1**  
Hilton Brussels Grand Place, Brussels, Belgium

1. Attendance and apologies
2. Minutes Spring Meeting Dublin 2016
3. "ICF-CY as a problem solving tool in complex pediatric cases"  
*Janneke Brandt, project assistant of our ICF-CY Meduse project, Medical School Hamburg, Germany (40 min with discussion)*
4. Report from the EU Commission Expert Group on Rare Disease (November 28-29th 2016, Luxembourg) *Liesbeth Siderius (10 min)*
5. Report from the Meeting of the Advisory Technical Group for the EU Platform on Rare Diseases Registration, (November 30<sup>th</sup>) Luxembourg, *Liesbeth Siderius (10 min)*
6. Report on Projects: FP7- Rare Best Practices : [www.rarebestpractices.eu](http://www.rarebestpractices.eu) meeting November 23- 24<sup>th</sup> Rome *Liesbeth Siderius (10 min)*
7. Report Multidisciplinary Joint Committee Rare and Undiagnosed Diseases, The kick-off meeting of the MJC RUD, 20<sup>th</sup> October 201 Brussels. *Liesbeth Siderius (10 min)*
8. General discussion activities in the field of rare diseases
  - patient and family involvement
  - interoperability
  - how to proceed?

LS November 13 th2016