



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



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

**Rare Disease Working Group
Saturday December 14th 2013 8.00- 9.30 Brussels**

1. Attendance and apologies
2. Minutes Meeting Brussels December 2012 (attached)
3. Projects: FP7- Rare Best Practices : www.rarebestpractices.eu/home
 - Joerg Meerpohl (Freiburg) : GRADE and distinctive features of rare diseases: how to get evidence?
 - Which diseases to select? Suggestions?
 - An EAP library of rare disease guidelines.
4. Comment on UNICEF/WHO discussion paper on Early Childhood Development and Disability(draft):
 - ICF-CY codes (WHO) for rare diseases
5. Any other business and proceedings

Looking forward to meet you in Brussels
on December 14th 2013
Liesbeth Siderius