

## Provisional Agenda Rare Disease WG

(EAP, UEMS Section of Paediatrics)

Bratislava, Slovakia Friday May 29<sup>th</sup> 2015,  
WG Rare Diseases 11.00- 12.30 **HALL A**

1. Attendance and apologies
2. Minutes Meeting Brussels December 2014 (attached)
3. Report from the EU Commission Expert Group on Rare Disease
  - Clinical trials in children <sup>1</sup>
  - Palliative Care in the European Union: Follow-up to informal Council discussions and proposals for a European Union framework of action
  - report of meeting March 12-13, 2015
4. Projects: FP7- Rare Best Practices : [www.rarebestpractices.eu](http://www.rarebestpractices.eu)
  - Help to appraise guidelines with the AGREE method
  - report of meetings
5. Any other bussiness and proceedings

<sup>1</sup>The European Commission and the European Medicines Agency would be interested to learn the perspective of experts and organisations acting in the field of rare diseases, given that a considerable percentage of paediatric diseases are rare diseases. To this end, we would be grateful if you could consider the following questions in order to facilitate the discussion (you can also send us your input in writing in advance of the meeting):

The recruitment of children in clinical trials is low, what do you think / know is the reason for this?

What are your main concerns on involvement of children in clinical trials

Are you aware of initiatives at national or international level working for further involvement of children in clinical trials?

If yes, which ones?

And which ones are the most successful?