

Provisional Agenda Rare Disease WG
(EAP, UEMS Section of Paediatrics)
Brussels, Friday, January 29, 2016, 11:00- 13:00

1. Attendance and appologies
2. Minutes Meeting Bratislava, 2014 (attached)
3. The importance of Open health data platform for developing comparable and interoperable patient registries rare diseases.
Tomaz Gornik, Ljubljana, Slovenia
4. Report from the EU Commission Expert Group on Rare Disease (12-13 november 2015)
5. What are your experiences with Expert Centres and Reference Networks?
6. Importance of Primary Care Pediatricians for children with a rare and disabling condition and Early Child Development
7. Projects: FP7- Rare Best Practices : www.rarebestpractices.eu
8. Any other business and proceedings