



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 1st 2017

WG Rare Diseases 9.30- 10.30

1. Attendance and apologies
2. Minutes Spring Meeting 2017
3. Report UEMS Multidisciplinary Joint Committee Rare and Undiagnosed Diseases
Liesbeth Siderius (15 min)

The right to access to highest standards of care of the most vulnerable children:

4. Making Roma Health and Early Childhood Development a priority for Europe.
Marius Lucian Tudor
Roma Health and Early Childhood Development Project Manager
European Public Health Alliance (EPHA)
(20 minutes)
5. From first feature, to gene, to society
Introduction Info Web Rare Diseases
Petra Poulissen, Patient Representative
The Netherlands
(20 minutes)

LS November 2, 2017