

Provisional Agenda Rare Disease WG

(EAP, UEMS Section of Paediatrics)

Dublin, Friday June 3rd 2016,

WG Rare Diseases 8:30- 10:00 **HALL A**

Davenport Hotel <http://www.davenporthotel.ie>

1. Attendance and apologies
2. Minutes Winter Meeting Brussels, 2015 (january 2016- attached)
3. Report from the EU Commission Expert Group on Rare Disease (april th5-6 2016)
Liesbeth Siderius (10 minutes) New recommendation on social services:
http://ec.europa.eu/health/rare_diseases/docs/recommendations_socialservices_policies_en.pdf
4. Report from the Meeting of the Advisory Technical Group for the EU Platform on Rare Diseases Registration, Luxembourg, 7 April 2016 and First Interoperability Workshop organised in the framework of the EU Platform on Rare Diseases Registration, Luxembourg, 7-8 April 2016. *Liesbeth Siderius (10 minutes)*
5. 'Rare Diseases in Ireland, the challenge of delivery of care in a small member state'.
Prof. Eileen Treacy, MD, FRCPI, FRCPC, FCCMG (20 minutes)
National Lead, Rare Diseases Clinical Programme
Clinical Professor- Inborn Errors of Metabolism, Trinity College Dublin
Clinical Professor-University College Dublin
National Centre for Inherited Metabolic Disorders
Children's University and Mater University Hospitals
6. Projects: FP7- Rare Best Practices : www.rarebestpractices.eu
Results and report of the General assembly April 28-29th Tenerife.
7. General discussion activities in the field of rare diseases

LS may 18 th2016