



EAP Winter Meeting 2019 | Brussels, Belgium

Rare Diseases Working Group
Friday, 6 Dec 2019 | 12.30 – 13.30

Chairs of Rare Diseases Working Group:
Risto Lapatto & Liesbeth Siderius

1. Welcome and Approval of Current Agenda & Minutes of the Spring Meeting in Vilnius, May 2019 (5 min)
2. Update on European Reference Networks (15 min) Risto Lapatto
3. The Impact of a Diagnosis: A Personal Account (5min) Saskia de Koster
Parent, the Netherlands
4. Sustainable Development Goals, Universal Health Coverage and Rare Diseases

What is the Least Paediatricians Can Contribute? (15 min) Liesbeth Siderius

Perspectives for collaboration with the European Academy Childhood Disability (10min) Prof Bernard Dan
Professor of
Neurophysiology and
Developmental Neurology,
Medical Director Inkendaal
Rehabilitation Hospital,
Université Libre de Bruxelles,
Belgium
5. Any other Business and General Discussion (10 min)