

AGENDA

CNA & CEF joint meeting

Thursday 26 November 2020

- 09.00-09.10 Welcome & Introduction of participants, *Yann Le Cam, facilitator*
- 09.10-09.45 Update on Rare 2030 and presentations from National Alliances, *Anna Kole*
- 09.45-10.45 Brussels Rare Disease Week 2021, *Kostas Aligiannis*
(including Rare Disease Day, Black pearl Awards and Rare 2030 conference)
- 10.45-11.00 Comfort Break*
- 11.00-12.00 Advocating toward a new European policy framework for rare diseases and how we could join all our forces to campaign together, *Valentina Bottarelli*
- 12.00-12.15 Comfort Break*
- 12.15-12.30 Recommendations to progress towards a mature ERN system, *Ines Hernando, Matt Johnson*
- 12.30-13.00 Discussion on how to disseminate and use this recommendations in advocacy work

Friday 27 November 2020

- 09.00-09.30 Update on RDI and International activities *Flaminia Macchia*
- 09.30-10.15 Update on Newborn Screening, *Gulcin Gumus*
- 10.15-10.30 Comfort Break*
- 10.30-11.30 Access to orphan medicinal products: where do we stand, *Simone Boselli*
- 11.30-12.00 A new pharmaceutical strategy for Europe - where do rare diseases fit, *Simone Boselli*
- 12.00-12.15 Comfort Break*
- 12.15-13.00 Manufacturing of Orphan Drugs in Europe, *François Houyez*
-