

Council of European Federations 5th Workshop

Paris, 30 & 31 Octobre 2012

Plateforme Maladies Rares, 96 rue Didot, 75014 Paris

Draft agenda

Tuesday 30 October

09.30-13.00 ***Joint Meeting CNA & CEF***

- 09.30-10.00 Creation of an Interest Group for translational research, *John Dart*
- 10.00-10.30 Access to treatments in the context of the crisis, *Yann Le Cam*
- 10.30-11.00 Coffee break
- 11.00-11.30 Specialised social services, *Raquel Castro*
- 11.30-12.00 Results of the off label use survey, *Rob Camp*
- 12.00-12.45 Cross Border Health Care - State of implementation at national level
- 12.45-14.00 Lunch CNA & CEF (room Petunia, - 1)

14.00-17.30 ***CEF meeting***

- 14.00-14.45 European Reference Networks (*Yann Le Cam*)
- 14.45-15.30 Support to European RD Federations 2013 (*Anja Helm/ Yann le Cam*)
- 16.30-16.00 Coffee break
- 16.00-17.00 Rare Connect for European RD Federations (*Denis Costello, Rob Pleticha*)



Wednesday 31 October

CEF training: "Research coordination & promotion"

- 09.30-10.00 Introductions & short presentation of on-going research activities of participants
- 10.00-10.30 TIRCON - Collaborative Research for a very rare disease as a global approach under FP7. Experiences of the German NBIA patient organization "Hoffnungsbaum e.V." as TIRCON-Partner, *Angelika Klucken*
- 10.30-11.00 Q&A, Discussion
- 11.00-11.30 Coffee break
- 11.30-12.00 The EURO-WABB Project (DH Health), an instrument to increase knowledge, improve the lives of affected people through better management, and to develop clinical research, *Kay Parkinson, Alström Europe & Partner EU WABB*
- 12.00-12.30 Q&A, Discussion
- 12.30-13.30 Lunch
- 13.30-15.30 From FP7 to Horizon 2020 – Funding opportunities for RD Research
Dr Gratiela Dobirta
- 15.30-16.00 Coffee break
- 16.00-16.30 Discussion & Conclusions

