

6th Workshop of the Council of European Federations

Paris, 29 & 30 October 2013

Room Primevere , Plateforme Maladies Rares, 96 rue Didot, 75014 Paris,

Draft Agenda

Tuesday 29 October

Joint Meeting CNA & CEF

09.30-10.30 European Year of Rare Diseases, *Sharon Ashton, EURORDIS*

- Update on launch activities by EURORDIS
- Discussion of the role of National Alliances
- Discussion on the implication of European Federations

10.30-11.00 Coffee break

11.00-12.00 Access to medicines campaign, *François Houyez, EURORDIS*

12.00-13.00 Social services, *Raquel Castro, EURORDIS*

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13.00-14.30 Lunch CNA & CEF (room Pervenche1st floor)
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CEF meeting

14.30-15.30 Registries, *Yann le Cam, Anna Kole, EURORDIS*

- Presentation of RD Connect
- Key principles & EUCERD recommendations
- Update on development at the European level (JRC – platform for RD registries)

15.30-16.00 Coffee break

16.00-17.00 Rare Best Practices – Information & update, *Juliette Senecat, EURORDIS*
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Wednesday 30 October

CEF training

09.30-10.00 Introductions & short description of on-going research activities of participants

10.00-11.00 Innovative Medicines Initiative (IMI), *Magda Gunn, Scientific Project Manager, IMI*

- Presentation of IMI and types of projects funded
- How can patient organisations participate in a research consortium?
- Participate in the discussion on priorities for the next IMI calls

11.00-11.30 Coffee break

11.30-12.30 Horizon 2020 and Rare Diseases - upcoming opportunities and constraints for RD research, *Valentina Botarelli, Eurordis*

- Wrap up FP7
- What do we know about Horizon 2020
- Links with IRDIRC

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12.30-14.00 Lunch
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Case studies: Research projects initiated & driven by patient organisations

14.00-15.00 Develop AKUre consortium & clinical trial, *Nick Sireau, AKU society*

15.00-16.00 Alliance Sanfilippo – Strategic Programmes, *Karen Aiach*

16.00-16.30 Discussion & Conclusions
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