

Agenda CEF Workshop

26-27 October 2017

Plateforme Maladies Rares, 96 rue Didot, 75014 Paris

Thursday 26 October

CNA & CEF Joint meeting

- 09.00-09.15 Welcome & introduction
- 09.15-10.00 RareConnect: new model & features, *Marta Campapadal*
- 10.00-10.20 Update on Rare Barometer and discussion on how to use the new survey on Rare Disease research, *Sandra Courbier*
- 10.20-10.45 OrphaCode: the implementation of RD coding in National Health Care systems and ERN, *Ana Rath, Orphanet*
- 10.45-11.00 *Coffee break*
- 11.00-12.00 Latest developments in ERN & ePAGs, *Lenja Wiehe*
- 12.00-12.30 European Pillar of Social Rights and next steps, *Annette Dumas*
- 12.30-13.00 EURORDIS position paper on social policy: process & proposed outline [for input] *Raquel Castro*
- 13.00-13.15 ECRD 2018 Vienna – What’s new? *Emilie Zingg*

13.15-14.30 *Lunch*

CEF meeting

- 14.30-15.000 Latest developments in EUNetHTA & future legislation, *Matteo Scarabelli*
- 15.00-15.30 Patient Engagement in scientific advice and rapid assessment, *Matteo Scarabelli*
- 15.30-16.00 HTA done properly - the Scottish experiment, *Russell Wheeler*
- 16.00-16.30 *Coffee break*
- 16.30-17.00 Patient engagement in EMA Scientific Advice, *Elisa Ferrer*
- 17.00-17.30 Peer to peer: sharing of experience and knowledge

Friday 27 October

CEF Training:

Community Advisory Boards – CAB

Moderators: François Houÿez, Rob Camp, EURORDIS

09.30-10:00 Introduction to the EURORDIS CAB Programme, *François Houÿez*

What a CAB is:

To guide the development of health technologies

- In vitro diagnostics
- Wearables, connected devices
- Implantable/invasive devices
- Complex surgery
- Medicines

What EURORDIS proposes to help members setting up their CAB:

- Guidance, mentoring
- Register, public section (Charter, MofU, Agendas) and private section
- Trainings
- Annual conference of CAB chairs and mentors
- Communication

10:00-11:30 Experience with CABs and suggestions on how to best operate them, *Rob Camp*

International (ACTG) and Europe in rare diseases: e-TSC (Tuberous Sclerosis Complex), CF-Europe, SS-ILD (Systemic Sclerosis - Interstitial Lung Disease)

11:30-11:45 Coffee break

11:45-12:30 Practical issues, *Rob Camp, François Houÿez*

- Call to members
- Main aspect to think of when preparing a CAB
- Organisational/Composition
- Deontological/ethical/confidentiality/insider trading prevention...
- Financial
- PRIME products / EUnetHTA Early Dialogues

12:30-13:30 Lunch

13:30-14:00 An example of a CAB in creation: CF-Europe CAB, *Hilde de Keyser, CF Europe*

14:00-15:30 CEF members present their Horizon Scanning results (refer to email describing the research you can do ahead of the CEF training)

- 8 federations will present their homework and how they see the creation of a CAB

15:30-16:00 Discussion with all, on the next steps

- Economic information (how much does a CAB cost?)
- How to evaluate the CAB contribution to research & development?

16:00-16:15 Update on the EMA policy on conflicts of interests

Supporting documents sent to participants one week prior to the meeting:

- Clinical Trial Charter
- Code of Practice for Members of Community Advisory Boards
- Call to Join a Community Advisory Board
- Check list for the creation of a CAB
