

# Council of European Federations

Paris, 14 & 15 October 2014

## Agenda

### CNA / CEF Joint meeting (from 09.30 to 14.30)

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09.30-10.30 **RareConnect**, *Denis Costello*

- Invitation to National Alliances and Federations to participate in new governance model
- Overview of new features and platform evolutions which will allow greater access to RareConnect through the introduction of Discussion groups on topics of relevance not just to diseases but to areas of interest across rare diseases

10.30-11.00 *Coffee break*

11.00-12.00 Rare Diseases International, *Yann le Cam, Flaminia Macchia*  
Objectives, Membership, Governance

12.00-12.30 Debrief: EUCERD Joint-Action Workshop on "Guiding Principles for Social Care in Rare Diseases" and next steps to the draft of the CERD recommendations in the social field, *Raquel Castro*

12.30-13.00 European Year for Rare Diseases – Update, *Sharon Ashton*

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13.30-14.30 *Lunch*

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### 14.30 CEF Meeting

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14.30-16.00 Information & Discussion: Organisation of Centers of Expertise and European Reference Networks by Therapeutic Areas, *Matt Johnson*

16.00-16.30 Coffee break

16.30-17.00 New procedure at the CHMP/EMA involving patients to oral explanation with the marketing authorization applicant, *François Houyez*



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# 15 October: CEF Training Session

## Registries

09.30-13.30

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**The how and why of disease registers, *Dr Anil Mehta, University of Dundee***

- Why are they important?
  - How do you implement them?
  - What are the challenges?
  - Consent
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*13.30-14.30 Lunch*

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14.30-15.00

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- **New resources in registry development, *Anna Kole, EURORDIS***
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15.00-16.00

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- **Questions & Answers**
  - **Discussion:**
    - Ethical & social aspects:
    - Registry uses
    - Funding (public/private partnerships)
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16.00-16.30

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Wrap up, *Yann Le Cam, EURORDIS*



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