

## 8<sup>th</sup> CEF Workshop

28-29 October 2015, Paris, Room Marguerite, Plateforme Maladies Rares, 96 rue Didot, 75014 Paris

### Agenda

#### Wednesday 28 October

#### CNA & CEF Joint meeting (from 09.30 to 13.00)

---

09.30-10.00 ECRD 2016 Edinburgh – Get involved! *Sharon Ashton*

10.00-11.00 The new RareConnect – Presentation + Why & how to get involved for NAs and EFs? *Denis Costello*

*11.00-11.30 Coffee break*

11.30-12.00 Inclusion of in-kind contributions into financial reports: Practice of EURORDIS, Guidance for EF & NA, *Patrice Regnier*

12.00-12.30 European Year of Rare Diseases, *Valentina Bottarelli*

12.30-13.00 Patient Voices Programme Plan, *Sandra Courbier*

---

*13.00-14.00 Lunch*

---

#### CEF meeting 14.00-17.00

---

14.00-14.30 Discussion of EURORDIS Membership Criteria for European Federations, *Yann le Cam*

14.30-15.00 RARE-Bestpractices project: how to retrieve, appraise and disseminate rare disease guidelines, *Juliette Senecat*

15.00-15.30 Rare Diseases International – Progress & Membership of International Federations, *Paloma Tejada*

*15.30-15.45 Coffee break*

15.45-16.15 Awareness Days –network building and communicating, *Lara Chappell*

16.15-16.45 INNOVCare project - innovation in social care provision for complex diseases, *Raquel Castro*

16.45-17.00 AOB



Thursday 29 October

## CEF Training

### European Reference Networks – Getting ready!

#### 10.00-12.30 *Understanding the process*

*Yann Le Cam, Matt Johnson*

This capacity building sessions' objective is to present the state of the art on how ERN will develop, look together at the application form, the criteria, the overall process, the constrains & flexibility,

- Overall process for the call and assessment of ERNs
- Assessment manual & tool box
- Application form for ERN
- Operational criteria

---

#### 12.30-14.00 *Lunch*

---

#### 14.00-16.00 *Engaging your organisation*

*Yann Le Cam, Matt Johnson*

This capacity building sessions aims to:

- Present the rare disease grouping
- Identify for which group of RD there is already an application under development
- Explain how EURORDIS is structuring its membership per rare disease grouping and the democratic representation of patients groups in each ERN and will support the exchange of experience across the different ERN

