

**Rare Diseases Task Force  
Working Group on Standards of Care  
Meeting on European Centres of Reference**

**Friday 3 June**

**11h00 – 16h00**

**Orphanet  
Bâtiment François de Gaudart d'Allaines, secteur jaune, porte 5  
Hôpital Broussais, 96 bis, rue Didot, 75014 PARIS**

**AGENDA**

- 10h30** Coffee served
- 11h00** Presentation of the EC DG SANCO High Level Group on Health Services and Medical Care Working Party on Centres of Reference. Expectations from the Working Group on Centres of Reference for Rare Diseases – *Marie-Madeleine Dautel, French Ministry of Health*
- 11h15** Presentation of the EC DG SANCO Rare Diseases Task Force and the Task Force Working Group on Standards of Care– *Ségolène Aymé, Orphanet and Leader of the Rare Diseases Task Force*
- 11h25** Presentation of the agenda for the day – *Edmund Jessop, UK Department of Health, leader of the Task Force Working Group on Standards of Healthcare*
- 11h30** Existing centres of reference for rare diseases in Europe. Presentations from:
- **France** (*Alexandra Fourcade, French Ministry of Health*)
  - **Italy** (*Domenica Taruscio, Istituto Superiore di Sanità, Italy*)
  - **Sweden** (*Christina Greek Winald, Swedish Centre for Rare Diseases*)
  - **Denmark** (*Dorthe Lysgaard, Danish Alliance of Rare Disorders*)
  - **UK** (*Edmund Jessop, UK Department of Health*)
  - **Spain – future plans** (*to be confirmed*)
- 12h50** Buffet lunch
- 13h30** Group discussion chaired by Edmund Jessop
- Definition of a European Centre of Reference for Rare Diseases
  - Process of qualification for European Centres of Reference for Rare Diseases
- 15h30** Conclusions and summary of points to be presented at High Level Group meeting in Brussels on 16 June
- 16h00** Meeting ends