

# Rare Diseases Task Force

## Working Group on Health Indicators

Monday 30 January 2006

10:00 – 17:00

Hôpital Broussais, 96 bis, rue Didot, 75014 PARIS  
Orphanet, building : Gaudart d'Allaines door n°5 (yellow sector), ground floor

### AGENDA

9:30 Coffee served

#### Session on Health indicators for rare diseases

10:00 Presentation of the Rare Diseases Task Force objectives in the field of health indicators – *Sécolène Aymé, RDTF leader*

Presentation of European Community Health Indicators project of DG Public Health in relation with Rare Diseases – *Juliette Bloch, Institut National de la Veille Sanitaire, Paris*

10:30 Discussion

10:45 Reports from an epidemiology survey in Extramadura – *Manuel Posada, Madrid*

11:00 Report on Health indicators in rare tumors – *Gemma Gatta, National Cancer Institute, Rome*

11:15 Report on Health indicators in rare diseases – *Dominica Taruscio, Istituto Superiore di Sanità, Rome*

11:30 Discussion on:

- purpose of collecting health indicators for rare diseases ?
- which indicators are appropriate ?
- possible sources at national level ?
- available expert resources

12:30 Buffet lunch

#### Session on Death certificates as a source of information

13:30 Death certificates collection and coding: Current practices in Europe and appropriateness for rare diseases – *Eric Jouglu, Inserm CépiDC, Paris*

14:00 Discussion

#### Session on Prioritisation of rare diseases

14:30 Prioritisation of rare diseases for epidemiological surveillance: how to proceed? – *Jean Donadieu, Institut de la Veille Sanitaire, Paris*

15:00 Discussion

15:30 **Coffee break**

15:45 **Session to prepare the workplan of the RDTF working group and a possible application to DG Public Health**

17:00 Meeting end