“National Strategies and Plans for Rare Diseases in Europe”
“State of the art and sharing experiences: toward EU Recommendations”

18 November 2008
Salle Laroque, French Ministry of Health,
Avenue Duquesne Paris VII

- Pre program -

09:30 am: Opening
French Minister for Health, Roselyne BACHELOT-NARQUIN

10:00 am: Introduction
Presentation of the European Commission Communication on Rare Diseases and Council Recommendation on Rare Diseases by Andrzej RYS, Director General, Public Health, European Commission

10:30 am: Session 1
Sharing experiences between Member States
Chair: Terkel ANDERSEN, Eurordis

- Overview of Member States policies for Rare Diseases: a 2008 update by Segolène AYMÉ, Chair of the Rare Disease Task Force

- Lessons learnt from national initiatives:
  - The Netherlands: The methodology of the Dutch Steering Committee on rare diseases and orphan drugs, Bert LEUFKENS (tbc)
  - Italy: Policies on rare diseases in a decentralised health care system, Domenica TARUSCIO
  - Bulgaria: Presentation of the Bulgarian National Plan, Rumen STEFANOV
  - Portugal: One year after the announcement of the plan, Jose ROBALO
France: Lessons learnt from 4 years of implementation of the national plan, Alexandra FOURCADE

Discussion with all participants

2:00 pm: Session 2
Towards EU Council Recommendation on Rare Disease National Plans
Chair: Frédérique RIES, Member European Parliament

- Presentation of EUROPLAN: European Project for Rare Diseases National Plans Development
  - A policy development project involving 19 Member States and patient organisations, Annalisa TRAMA
  - Needs and expectations from participants: a discussion based on analysis of questionnaire to participants, Domenica TARUSCIO with a Panel of key leaders from EUROPLAN: collecting national measures, health indicators, identification of best practices


Discussion with all participants

- Evaluation of national strategy and plan on rare diseases: Luciano VITTOZZI and Gil TCHERNIA

4:00 pm Panel of Policy makers (chaired by Frédérique REIS)
Discussants from EU Presidency troika (France, Czech Republic, Sweden) + European Commission + USA (NIH)

4:45 pm: Closing remarks
EU Commissioner for Health, Ms Androulla VASSILIOU