"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 Draft Commission Communication and Recommendation on Rare Diseases

10:30 am: Session 1
Sharing experiences between Member States
  - Overview of Member States policies for Rare Diseases: a 2008 update
  - Lessons learnt from national initiatives:
    - The Netherlands: The methodology of the Dutch Steering Committee on rare diseases and orphan drugs,
    - Italy: Policies on rare diseases in a decentralised health care system,
    - Bulgaria: Presentation of the Bulgarian National Plan,
    - Portugal: One year after the announcement of the plan,
• France: Lessons learnt from 4 years of implementation of the national plan.

Discussion with all participants

2:00 pm: Session 2
Towards EU Council Recommendation on Rare Disease National Plans

- Presentation of EUROPLAN: European Project for Rare Diseases National Plans Development
  • A policy development project involving 19 Member States and patient organisations,
  • Needs and expectations from participants: a discussion based on analysis of questionnaire to participants,

- Recommendations from European rare disease patients: Research, Centres of Expertise and European Reference Networks, Information, Access to care and orphan drugs. Empowerment of patient organisations.

Discussion with all participants

- Evaluation of national strategy and plan on rare diseases.

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

4:45 pm: Closing remarks