



**“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**

