



6th Workshop
Eurordis Round Table of Companies

"Do Rare Disease Patients Have Real Access to Orphan Drugs in Europe? "

July 9th, 2007
Barcelona, Spain

Fundació Doctor Robert - Universitat Autònoma de Barcelona- Casa Convalescència

Programme

8:30 Welcome & coffee

MORNING 9:00 - 12:50

Chairpersons:

Ad Schuurman (President of MEDEV) - Josep Torrent-Farnell (COMP member)

9:00 - 9:15 Welcome address

9:15 - 9:55 "Eurordis' survey on orphan drugs availability in Europe"
(Fabrizia Bignami, Eurordis)

9:55 -10:05 "Concept of confidentiality of medicinal product prices and of number of patients treated"
(Josep Torrent-Farnell, COMP member nominated by Spain)

10:05 -10:40 Discussion (35')

Transparency on the conditions of availability, real coverage of all potential patient population, conditions of access for patients, scenario planning: how many orphan drugs in the EU in 5 years? 10 years?

10:40 - 11.00 – COFFEE BREAK

11:00 – 12:00 "Learning and exchanging information about EU Member States` experience with orphan drugs"
(representatives from Competent Authorities: Belgium, Hungary, Italy, the Slovak Republic, Spain, Sweden, UK)

12:00 – 12:50 Discussion (50')

12:50-14:00 – LUNCH

AFTERNOON 14:00 -16:30

Chairpersons:

Yann Le Cam (Chief Executive Officer of Eurordis) – François Meyer (Haute Autorité de Santé)

14:00 -14:30 *“Specific value of orphan drug status and obstacles to patients’ access to OMPs in Europe”*

(David Meeker, Genzyme - Bertrand Bonnot, Actelion)

14:30 -14:55 *“Collaboration between HTA agencies for common approaches on orphan drugs “*

(François Meyer, HAS- France)

14:55 -15:25 *“The payers’ point of view: possibility of a common assessment of a new orphan drug and price/volume discussion”*

(Ad Schuurman, President of MEDEV)

15:25 -16:30 *Discussion with panel including all stakeholders*

Panel members:

Afternoon speakers

Eric Viaud, Gene Signal

Bernard Dauvergne, Addmedica

16:30

End of Workshop