

Rare Disease Day



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European Workshop

Bridging Patients and Researchers to Build the Future Agenda for Rare Disease Research in Europe

Monday, March 1st, 2010

Centre de Presse International (IPC), Résidence Palace, Rue de la Loi 155,
Brussels, Belgium

08.30 – 9.00	Registration
9.00 – 9.15	Opening Speech by Robert Madelin, Director General Health and Consumers, European Commission (EU)
Morning session:	What are the priorities in rare disease research? Researcher's and Patient's needs and expectations
Chairperson	Volker Straub, Coordinator of the Treat NMD project, Newcastle University Terkel Andersen, President of Eurordis
09.15-09.45	Orphanet – Presentation of the RD Platform fact finding study on the determinants of rare disease research trends Ségolène Aymé, Director of Orphanet
09.45-10.00	Q & A
10.00-10.30	The E-Rare Network - Presentation of results from survey on scientists' and policy-makers' research priorities in the field of rare diseases Manuel Posada, Instituto de Salud Carlos III, Spain
10.30-10.45	Q & A
10.45-11.00	Coffee break
11.00-11.30	EURORDIS – Results of survey on the role of Patient Groups in Research and their priorities for the future Fabrizia Bignami, Therapeutic Development Director of Eurordis
11.30-11.45	Q & A
11.45-12.45	Panel discussion chaired by Segolène Aymé, Director of Orphanet Participants: Birgit Wetterauer, BMBF, Germany Miikka Vikkula, Université Catholique de Louvain, Belgium Avril Daly, Fighting Blindness, Ireland Harrie Seeverens, Ministry of Health The Netherlands
	Discussion:
	<ul style="list-style-type: none"> ▪ Bridging the gap between researchers and patients to boost rare diseases research ▪ Expectations and needs at the national level concerning research on rare diseases ▪ Which priority for resource allocation at the EU and National level in rare diseases?

12.45-14.00

Lunch

Afternoon session:

How to develop a strong policy to advance rare disease research?

Chairpersons

*Kerstin Westermark Chairperson of the Committee on Orphan Medicinal Products at the European Medicines Agency (EMA)
Anders Olauson, Eurordis, European Patient Forum and Member of DG Research Advisory Board*

14.00–14.25

The European Commission in rare disease research

Manuel Hallen, Head of Unit – Medical & Public Health Research - DG Research, European Commission (EU)

14.25-14.45

Mini debate: What place and which strategy for rare diseases in FP8?

14.45- 15.10

Presentation of the E-Rare Network

Sophie Koutouzov, E-Rare Coordinator

15.10-15.30

***Mini debate: How to ensure that other Member States join the network?
How to best coordinate the national and the European efforts?***

15.30-16.00

EUROPLAN –Presentation of the Recommendations to support Rare Disease Research through National Plans and Strategies

Domenica Taruscio, Istituto Superiore di Sanita, EuroPlan Project Leader

16.00-16.15

Mini debate: What has to be done at the national level to ensure that local actions coordinate with international activities (EU networks of centres of expertise and EU research networks)?

16.15-16.45

Why and how to invest in rare disease research

Take home message – Conclusions and Recommendations

Yann Le Cam, CEO of Eurordis

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