Clinical research:

How to involve patient representatives as experts Moderator: Arrigo Schieppati Istituto Mario Negri, Italy

- Key issues in understanding clinical trials, evaluation of pilot training sessions: Flaminia Bansgaard Eurordis
- Patient as experts:

sharing protocol design experience acquired:

Francois Faurisson Eurordis

Patients' voice: making it loud and clear Moderator: Jean Elie Vaincre la Mucoviscidose, France

Lessons learnt from EurordisCare 1 & 2: moving towards EurordisCare 3:

Fabrizia Bignami Eurordis

Discussion How can study results be used for advocacy?

■ Lessons learnt from judgements of the **EU Court of Justice:**

> Francesco Ronfini. Regione Veneto, Brussels office

Discussion How can ECJ judgements be used for advocacy?

17h30 to 19h00

Workshop participants who wish to do so can continue informal discussion with their Workshop's speakers & moderators

19h15 to 20h15 Guided tour of San Marco Basilica

20h30 to 23h00 Goodbye dinner (courtesy of Genzyme Italy) We wish to thank the following for their generous support:











FARMINDUSTRIA

This event was made possible thanks to:

Cassa di Risparmio di Venezia

Fondazione di Venezia







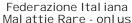




EURORDIS European Organisation for Rare Diseases



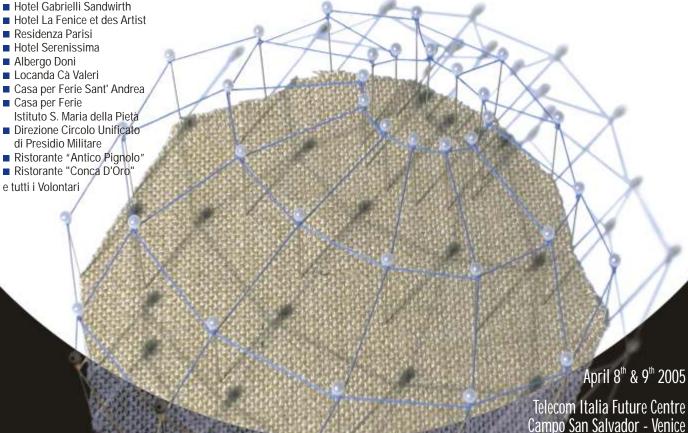
UNIAMO





2005 Membership Meeting: **Building a Community**

Istituto Superiore di Sanità - Regione del Veneto - Provincia di Venezia - Città di Venezia



Friday April 8th

10h00 to 12h00 Council of National Alliances Informal Meeting (CNA members & observers only)

13h00 to 14h00 Annual General Assembly Registration & Welcome Coffee (Eurordis members only)

14h00 to 17h00

Eurordis Annual General Assembly 2005

Business Agenda & Election of Directors
 Debate on Eurordis Strategy & Orientations 2006

17h00 to 17h30 Coffee Break

17h00 to 17h30
Eurordis Board of Directors Meeting
& Election of Officers
(Directors only)

17h30 to 20h00 European Public Affairs Committee Meeting (EPAC members only)

20h30 Membership Dinner (courtesy of Genzyme Europe)

Saturday April 9th

Access to Diagnosis & Care Conference

9h00 to 9h30 Registration

9h30 to 9h45 Welcome message:

Terkel Andersen President Eurordis

Opening address:

Loredana Nasta President UNIAMO

9h45 to 11h00
The long & winding road:
obtaining a diagnosis for rare disease patients
Moderator: Yann Le Cam
Eurordis

Results of EurordisCare 2 study of access to diagnosis for 8 rare diseases in 21 countries, including Italy (25'):

Marie-Christine de la Morlais, Steering Committee EurordisCare 2

Panel discussion:

5 disease-specific network representatives (20')

Cystic Fibrosis: Judy Windle

GIDO, Ireland

■ Duchenne muscular dystrophy:

Silvia Starita

Parent Project, Italy

Parent Project, II
■ Ehlers Danlos:

Britta Berglund EDS Riksförbund, Sweden

■ Marfan:

Lukasz Westwalewicz MarFan Polska, Poland

Prader-Willi syndrome:

Valentino Colosso Prader Willi, Italy

Debate (30')

11h00 to 11h30 Coffee break 11h30 to 13h00

Improving access to diagnosis and care Moderator: Domenica Taruscio Istituto Superiore di Sanitá

Presentation of recent rare disease initiatives

 French rare disease plan 2005-2008, adopted in 2004: Christel Nourissier
 France (20')

Italian rare disease plan:

Maria Elena Congiu Italian Health Ministry (10')

Spanish rare disease diagnosis initiative:

Domingo Gonzalez Lamuño Spain (10')

Panel discussion with patient representatives participating in these initiatives (20')

Torben Grønnebæk KMS, Denmark Loredana Nasta UNIAMO, Italy Rosa Sanchez de Vega FEDER, Spain

Debate (30')

13h00 to 13h10 Supporting rare disease research Francesca Sofia Telethon Italia

13h10 to 13h20 Conference message Michele Lipucci di Paola Vice-president, Eurordis

13h20 to 15h30 Buffet lunch

15h30 to 17h30
Patient Empowerment: 3 Paral

Patient Empowerment: 3 Parallel Workshops

Internet: How to find validated rare disease information
Moderator: Bruno Dallapiccola
Orphanet, Italy

■ How to find & evaluate rare disease information on the Web:

David Oziel, France