

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 Banggaard
Eurordis
- Patient as experts:
sharing protocol design experience acquired:
François 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:



This event was made possible thanks to:

- Cassa di Risparmio di Venezia
- Hotel Gabrielli Sandwirth
- Hotel La Fenice et des Artist
- Residenza Parisi
- Hotel Serenissima
- Albergo Doni
- Locanda Cà Valeri
- Casa per Ferie Sant' Andrea
- Casa per Ferie
- Istituto S. Maria della Pietà
- Direzione Circolo Unificato di Presidio Militare
- Ristorante "Antico Pignolo"
- Ristorante "Conca D'Oro"
- e tutti i Volontari



UNIAMO

Federazione Italiana
Malattie Rare - onlus

2005 Membership Meeting: Building a Community



April 8th & 9th 2005

Telecom Italia Future Centre
Campo San Salvador - Venice

Con il Patrocinio di:
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

■ 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 Sanità

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 Grønnebak
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 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