

EUROPEAN GENETIC ALLIANCE
Munich, International Congress Centre, June 12-15, 2004
Program

*VOICING THE INTERESTS OF PATIENTS & FAMILIES
on the issues of timely diagnosis & effective treatment
IN THE POLITICAL AND SCIENTIFIC ARENA*

BENEFITTING FROM GENETICS, GENOMICS & BIOTECHNOLOGY

Saturday, 12 June 2004

- 15:45 Opening Ceremony of the European Society of Human Genetics Conference
- 20:00 Welcome Reception Hall ESHG
Informal get together

Sunday, 13 June 2004

- 09:00 Meeting European Genetic Alliance Room 12
Policy, priorities, program/workplan, procedures Invitation Only
Streamlining programs
National Genetic Alliances
CEE – Genetic Network
Disease spec. European Alliances
- 15:00 European Genetic Alliance Meeting in collaboration with other patient alliances: Room 12
Open Session

Chair: Alastair Kent (GIG)/ Michael Griffith (FB)

The role of patient alliances in influencing healthcare policy and R&D. The American model

Patrick Terry, President International Genetic Alliance

The Australasian model

Dianne Petri -tbc, CEO of the Australasian Genetic Alliance

Views from practice

Piraye Serdaroglu, Turkey

President World Alliance Neuromuscular Disorder Associations

Former President European Alliance Neuromuscular Disorder Associations

The International Pompe Association as a model for Approaches in rare disorders

Maryze Schoneveld van der Linde, Boardmember IPA

A vision statement

Ad van Bellen, Chairman HEART EU

Sunday, 13 June 2004 (cont'd)

The role of the European Patient Forum

Jean Georges, Secretary General European Patient Forum

*The role of the European Platform Patient Organisations,
Science and Industry (EPPOSI)*

Ysbrand Poortman, Chairman EPPOSI

16:30 Coffee Break

16:45 The Collaboration, a round-table conference
Opinions patient organisations

Room 12

Joint ventures / proposed projects:

Support Centre for Patient Organisations

Major Projects (GENGUIDE, EUROGENTEST, GENED..)

18:00 Conclusions / Closure

20:00 RECEPTION

State reception and evening in the World Famous 'Hofbräuhaus'
in Munich

Monday, 14 June 2004

GENETIC TESTING (*Session organised in collaboration with EDMA*)

Room 12

Open session

Chair: Jean Georges (EPF)

Co-Chair : Prof. Jean Jacques Cassiman

09:00 Introduction

Personal accounts from practice regarding diagnosis & testing
Alastair Kent

09:10 *Gene chips and population screening*

Dr. Tom Metcalfe

Senior Vice President, Head of Roche Biomarker Program

09:30 *Pharmaco Genetic Testing: New achievements, opportunities and
bottlenecks*

Prof. Klaus Lindpainter

Roche Genetics, Basel

09:50 *Access to and reimbursement for clinically necessary tests*

Prof. Jorg Schmidtke

School of Medicine, Hannover

ESHG, PPP – Committee

10:10 *Improving the quality of genetic testing in Europe*

*Recommendations of the EU/strata group implemented in the
EU/DG Research Eurogentest project*

Prof. Jean Jacques Cassiman

Human Genetics, University of Leuven

Monday, 14 June 2004 (cont'd)

- 10:30 *Genetic testing and decision-making procedures
Recommendations of the EU/Strata group implemented in the
EU/DG Research EGA/Euroguide project*
Alastair Kent
Genetic Interest Group & Member Strata group
- 10:45 Coffee Break
- PAEDIATRIC RESEARCH IN MEDICINE Room 12
(Session organised in collaboration with EFPIA)
Chair: Cor Oosterwijk (VSOP)
Co-Chair: Daniel Vasman (Aventis/EFPIA)
- 11:00 *More, better, faster and available medicines - view from the
patient perspective*
Ysbrand Poortman
- 11:15 *New safe medicines faster: A public- private partnership for
revision of the R&D process*
Dr. Jorgen Dirach, MD, MBA
Novo Nordisk, Director Research Affairs
- 11:35 *Research based pharmaceutical industry perspective on paediatric
medicines*
(tbc)
- 11:55 *The Commission's draft Regulation on Paediatric Medicines and
the legislative process*
Dr. Daniel Vasman M.D., Ph.D.
Aventis, EFPIA paediatrics working group
- 12:15 *Critical issues of children with rare disorders and the views of
Eurordis*
Michelle Lipucci
Eurordis (tbc)
- 12:35 *Innovative therapies – gene therapy, stem cells and
biotechnological drugs. View from the patient perspective.*
Alastair Kent / Maryze Schonevel van der Linde
- 12:50 Lunch
- 13:30 MORE AND BETTER PAEDIATRIC MEDICINES THROUGH Room 12
INNOVATIVE RESEARCH Invitation Only
Streamlining opinions and activities of patient alliances towards
genetic testing and paediatric research - Working Conference
Chair: Alastair Kent
- 15:30 Coffee Break

Monday, 14 June 2004 (cont'd)

16:00 EPPOSI DEBATE
EU ENLARGEMENT, Bottlenecks and Opportunities
Chair: Dr. David Bennett and Michael Griffith

Room 12
Invitation Only

Introduction

Ysbrand Poortman, Chairman EPPOSI

The EU/DG Sanco view

Dr. Pavel Telicka, (provisionally confirmed), Czech Republic
Commissioner DG-Sanco, European Commission

*Opportunities for CEE- scientists to integrate in western
research programs*

Prof. Jean Jacques Cassiman, Belgium

Liaison officer Int'l Federation Human Genetic Societies

The EFB view

Dr. David Bennett, Netherlands

Secretary General European Federation of Biotechnology

The Industry views and experience

Dr. Ute Stozle, Germany

Vice President & General Manager Genzyme CEEC

The Views of the CEE-Genetic Network

Grzegorz Wegrzyn, Poland

Chairman CEE-GN,

Chairman Polish Mucosaccharidoses parent/patient alliance

*5 minutes statements by European patient alliances
expressing their views and activities*

19:00 Reception / Welcome Drink

Prinzregent Hotel

19:30 DINNER MEETING

RiemerStrasse 350

Chair: Andrea Rappagliosi, Serono

Invitation Only

5 minutes presentations by ESHG, EDMA, EFPIA, EGA

1st course EU/25, top priorities and practical advice

Dr. Pavel Telicka

2nd course Patient organisations and medico social challenges, priorities
and practical advice

Barbara Czeisel

3rd course Rapporteurs

Coffee Conclusions, recommendations

Alastair Kent

22:15 Closure

Tuesday, 15 June 2004

09:00 Meeting European Genetic Alliance
Reports, conclusions, decisions

Room (tbc)
Invitation only

Z:_EGA\Munich\draft Munich Program 10 May 2004.doc