

Annual EGAN Conference
organised in conjunction with the
European Human Genetics Conference
Amsterdam RAI, 7 & 8 May 2006

Organised by



in partnership with



Sponsored by

DSM Food Specialties
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EGAN

EGAN - European Genetic Alliances' Network - is the European association of patient organisations, representing either one specific condition on a multi-country level or several conditions on a national basis, with specific interest in genetics, genomics and medical biotechnology. EGAN wants genetic, multi factorial and congenital conditions to be understood, early diagnosed, prevented and/or effectively treated. The association creates a voice for patients in European health policy and research.

booth number RL-2
www.egaweb.org
invitations: +31 35 603 40 40

EPPOSI

The European Platform for Patients' Organisations, Science and Industry EPPOSI is an EU patient-led partnership between patient organisations, industry and academic science and clinicians, founded in 1994 to discuss and influence policies in human healthcare in Europe based on joint views by its stakeholders.

www.epposi.org

PROGRAMME

SUNDAY, 7 MAY 2006

EUROPEAN PROJECTS

Room E & F - *INVITATION ON REQUEST*

8.45 – 12.15

WORKING CONFERENCE ON EU/DG RESEARCH FP6 PROJECTS:

- **EUROGENTEST** - Genetic testing in Europe
- **EUROGENGUIDE** - A consensus guide to getting involved in genetic research
- **CONSERT** - Gene therapy for inherited disease

14.45– 18.40

EPPOSI CONFERENCE, see detailed programme next page

19.15 - 22.00

**EPPOSI RECEPTION AND DINNER DEBATE, on invitation only
(request invitation: phone +31 35 603 40 40)**

EPPOSI CONFERENCE
DATA- AND BIO-BANKING FOR RESEARCH:
TOWARDS JOINT VENTURES OF PATIENT ORGANISATIONS, SCIENCE AND INDUSTRY
ON THE ROAD TO VALIDATED EXPERTISE AND NEW THERAPIES

Room E & F - *OPEN SESSION*

Chair: M. Griffith

14.45 - 14.50	Welcome and Introduction	M. Griffith, EPPOSI, Brussels, Belgium
	Patients towards joint-ventures	
14.50 - 15.05	Biobanking by Patient Organisations, the USA Experience	P. Terry, International Genetic Alliance, USA
15.05 - 15.20	The Role of Patients in Biobanking for Rare Diseases In Europe	V. Karcagi, EuroBioBank, Hungary
15.20 - 15.35	Patient Organizations as Owners and Managers of their Data and Tissue	J. Bovenberg, Academic Medical Centre Amsterdam, The Netherlands
15.35 - 16.00	<i>Patient reports</i>	
	– The Pompe Survey: Collaboration of Science and Patients.	R. Broekgaarden, IPA / Erasmus University Rotterdam, The Netherlands
	– ENRAH: Collaboration of Science and Patients in the Setting Up of Patient Registries	T. Schyns, ENRAH, Vienna, Austria
	– Science and Industry Collaboration in Bio-banking for Crohn's Disease	R. Mitchell, EFCCA, UK, in cooperation with Academic Medical Centre Amsterdam
	Science towards joint-ventures	
16.00 - 16.20	UK Bio Banks Standards	MRC DNA Banking Network, Cambridge, UK
16.20 - 16.40	National Biobanks in Iceland, Estonia and UK	K. Stefánsson, deCODE genetics, Iceland
16.40 - 17.00	Coffee Break	
17.00 - 17.15	The Value of Biobanks for Human Genetics	A. Metspalu, ESHG President
17.15 - 17.30	Patient Registries, a Useful Tool for Exchange between Researchers (title tbc)	O. Cohen, HC Forum, France
	Industry towards joint-ventures	
17.30 - 17.50	Biobanking: The Next Step to Personalised Healthcare	M. Hehenburger, IBM, US tbc
17.50 - 18.05	The Role of Pharmaceutical Industry	D. Niese, Novartis, Basel, Switzerland
	The view of Regulators/Authorities	
18.05 - 18.20	A Supportive and Anticipating Regulatory System for Biobanks across Europe.	J. Kaye, University of Oxford, UK
18.20- 18.40	Discussion and Summary: The Way Towards Joint Venture of Patient organisations, Science and Industry	A. Kent, EPPOSI/EGAN/GIG Brussels/London, Belgium/UK
19.15 - 22.00	EPPOSI Reception and Dinner Debate ON INVITATION ONLY (request invitation: +31 35 6034040)	

The EPPOSI Conference is sponsored by IBM, Novartis, Amgen, Biogen and Genzyme

MONDAY, 8 MAY 2006

ASSEMBLY

Room E & F - *INVITATION ON REQUEST*

8.45 – 10.15 **EGAN ASSEMBLY**

10.15 - 11.15 **ROUND TABLE MEETING EUROPEAN GENETIC RESOURCE AND INFORMATION POINT**

NUTRITION, GENETICS/GENOMICS AND THE PREVENTION AND MANAGEMENT OF DISEASE

In cooperation with DSM FOOD SPECIALTIES

Room E & F - *OPEN SESSION (lunch included)*

Chair: A. van Bellen and C. Smit

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| 11.15 - 11.25 | The Role of Patient Alliances in the Prevention and Management of Chronic/Genetic Disease | Y. Poortman, IGA, vice president, The Netherlands |
| 11.25 - 11.45 | The Role of Genetics/Genomics in Nutritional Strategies in the Prevention and Management of Disease | M. Müller, Wageningen University, The Netherlands |
| 11.45 - 12.05 | The Role of Periconceptional Nutrition on Health in Early and Later Life: New Scientific Insights | R. Steegers, Erasmus MC, Rotterdam, The Netherlands |
| 12.05 - 12.25 | The Role of Food Industry | P. Rijken, DSM Food Specialties, The Netherlands |
| 12.25 - 12.45 | Need for Early Detection, Accurate Diagnosis and Fast Application of Nutritional Medication - Patient Reports | K. van Bezooijen – ECPC
A. van Bellen – HEART EU |
| 12.45 - 13.05 | Expectations towards Nutritional Medication in Chronic Disease | Panel discussion |
| 13.05 - 13.15 | Summary and Closure | |

ROUND TABLE MEETING
**PREVENTION AND EARLY DETECTION OF GENETIC DISEASE
IN THE PRECONCEPTION, NEONATAL AND CHILDHOOD PHASE**

Room E & F - *OPEN SESSION*
Chair: C. Oosterwijk and T. Schyns

15.00 - 15.05	Welcome and Introduction	C. Oosterwijk, EGAN/VSOP, Soestdijk, The Netherlands
15.05- 15.25	The Prevalence Rates of Genetic and Congenital Disease in Europe	I. Barisic, Eurocat, Croatia
15.25 - 15.45	Incorporation of Preconception Care in General Health Care	E. Steegers, Erasmus University Rotterdam, The Netherlands
15.45 - 16.05	Recent Progress in Neonatal Screening Options: A Challenge for Europe	G. Loeber, Institute for Public Health and Environment, RIVM, Bilthoven, The Netherlands
16.05 - 16.25	Early Detection and Preventive Management of Genetic Syndromes in Minors	C. Schrandt, Maastricht University, The Netherlands
16.25- 16.45	Break	
16.45 - 17.05	Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention: New Initiatives	I. Nippert, World Alliance Orgs. for Prevention & Treatment Genetic Disease, Munster University, Germany
17.05 - 17.25	Integration of Genomics into Public Health Policies and Health Services - European Perspectives and Initiatives	A. Brand, German Center for Public Health Genomics, Bielefeld, Germany
17.25 - 17.45	Patient reports: The Role of Patient Organisations in Prevention and Early Detection	Y. van der Wiel-Rompa, Retina Nederland, The Netherlands tbc And others
17.45 - 18.30	Discussion	

This meeting is sponsored by DIAGNED, the Diagnostics Association of the Netherlands

Proposed programmes as per date of printing



Secretariat: Vredenhofstraat 31 Soestdijk The Netherlands,
Phone +31 (0) 35 603 40 40 Fax +31 (0) 35 602 74 40
www.egaweb.org E-mail j.staalstra@vsop.nl