

Appendix 4

**Programme of the 16th EUROCAT
Registry Leaders' Meeting, Catania,
Sicily, 1-4 June 2001**

REGISTRY LEADERS'S MEETING SICILY, JUNE 2001

Friday 1 June: Registry Leaders Meeting

[1.00] Coffee and registration for RLM

Afternoon Chair: David Lillis

[2.00] Welcome, apologies and minutes of last meeting.
Adoption of the Agenda
Project Leader's Report
Is EUROCAT meeting its aims and objectives?
Presentation of Progress Report
Organisation of Central Registry
What we are contracted to do under RDP
What we should achieve during this meeting
Membership of working groups and committees

[2.30] Reports from Working Groups (Kelly, Goujard, Dolk, Busby, Vrijheid)
Aims and objectives and mode of operation
Progress to date
Objectives during RLM

[2.50] EUROCAT budget (Norton)

[2.55] Discussion of Progress Report

[3.15] Break

[3.45 – 5.45] Subgroup Meetings (Four parallel groups)
Hypospadias Project (chair: Dolk)
Communication and Ethics Working Group (chair: Busby, one hour only)
Data Quality Committee (chair: Vrijheid)
Drugs during Pregnancy (chair: Irgens)
OR Set up posters for symposium

Saturday 2 June

Scientific Symposium

Sunday 3 June

Chair: Marie-Claude Addor

- [9.00] Data management – new directions (Dolk)
- [9.10] Presentation of the new EUROCAT data management and validation programme(EDMP) [Densem, Biomedical Computing Ltd]
- [9.40] The state of the EUROCAT database [Rosato]
- [9.50] Ethics and confidentiality issues (Ritvanen)
- [10.00] General Discussion on data transmission, use of EDMP, extended vs core vs aggregated dataset, confidentiality.
- [10.30] Break and opportunity to view new EDMP
- [11.00–1.00] Opportunity to view new EDMP **OR**
Subgroup Meetings (*two parallel groups*)
NTD and folic acid (Chair: Abramsky)
Classification and Coding Committee (Chair: Vrijheid)

Afternoon: Organised trip to see the sights of Sicily.

Monday 4 June

Morning Chair: Catherine de Vigan

**8.30 – 9.30 Further Discussion of Progress report
Discussion of local registry reports.
Presentations by new and applicant registries: Poland**

9.30 – 12.30 Data quality workshop : Problems and solutions.

- [9.30] How to register Hypspadias – new guidelines from the Hypospadias study and prospective study protocol: (Dolk)
- [9.40] Type of Birth (Dolk)
- [9.45] Data quality standards – a new approach. (Vrijheid)
Focus on maternal occupation and one week survival.
- [10.00] Registry descriptions – achieving clarity and standards (Busby)
- [10.10] Maternal age: Ensuring correspondance between numerators and denominators (Wiesel).
Ascertainment Panel Study Aims (Wiesel)

- [10.40] Break

- [11.00] Panel discussion. Questions, answers and discussion regarding malformation coding: All RLs to submit questions (preferably in advance) to Classification and Coding Committee (Panel: Tenconi, Calzolari, Stoll, Ritvanen, Garne, Vrijheid (chair)). Panel will also make short presentations on areas such as coding problems observed in research projects, coding of chromosomal deletions, ICD10, neoplasms and metabolic conditions, minor anomalies, syndrome coding.

- 12.30 Lunch

Afternoon:

- 1.30-2.30 Subgroup meetings (one hour only, two parallel groups)
Prenatal Diagnosis (Chair: Ester Garne)
Ascertainment Panel Study (Chair: Wiesel)
Preparation of ESRAR (Chair: Bianchi)

2.30-3.30 Reserved time for EUROCAT association: election of steering committee and other business.

Afternoon Chair: Janine Goujard

- [3.30] Proposals for RLMs in 2002,2003,2004. Decision on venues and frequency.
[3.45] Break

4.15–5.40 Surveillance and research directions:

- [4.10] Prospects for statistical surveillance locally and at central level. Report of WG on Statistics and Surveillance. (Kelly)
- [4.25] Structure of EUROCAT Report 8 (Dolk)
- [4.40-5.40] Reports from Research projects and presentation of new project ideas
FOCAL study (follow-up of children born with congenital anomalies) (Abramsky)
NTD and folic acid project group (Abramsky)
Ongoing folic acid studies (Kirke)
Geographical Variation project (Calzolari)
Socioeconomic and geographic variation in UK (Vrijheid)
Comparative panel on ascertainment of congenital anomalies (Wiesel)
ESF/EUROCRAN and related projects (Calzolari)
Prenatal diagnosis of cardiac defects (Garne)
Multiple births (Dolk)
Case-control study of congenital heart disease (Vrijheid)
EUROSCAN II (Stoll)
DNA Laboratory index (Gillerot)
New projects presented by RLs
How should research projects be used to sustain EUROCAT through financial gaps? (Dolk)
- [5.40] **News from related networks**
- [5.40] News from British Isles Network of Congenital Anomaly Registers (BINOCAR) (Botting)
- [5.45] News from Italian registry network (Bianchi)
- [5.50] News from ICBDMs (Robert), collaboration with ICBDMs (Bianchi), potential models of ICBDMs-EUROCAT collaboration (Dolk)
- [6.10] Presentation of NEPHIRD project (Bianchi)
- [6.15] Advanced Reprod Risk assessment course (ESRAR): programme (Bianchi)
- [6.25] **Closing Remarks**

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