“EuroNeoStat” Project
A European Information System to Monitor Short- and Long-Term Morbidity Outcomes to Improve Quality of Care and Patient-Safety for Very-Low-Birth-Weight (VLBW) Infants (2005-116)

Adolf Valls i Soler
Prof. Paediatrics
Univer. Basque Country, Bilbao, Spain
DG SANCO
4th meeting of the TFMCD
Luxembourg, December 13th 2006
Is an Epidemiological I.S. for VLBWI needed?

- Prematurity rates are increasing
- Outcomes of VLBW infants contribute significantly to Neonatal and Infant mortality (up to 80 - 90%)
- Are a small number of cases (1-2% of total livebirths)
- All cases are immediately identified in hospitals
- Large and increasing amount of health resources are consumed (Short- long-term)
- Initial risk similar, so outcome directly related to quality of care
- There are several Evidenced-based interventions to improve outcomes (Antenatal steroids, surfactant)
- Nosocomial infection is still one of the principal problems (Preventable)
Neonatal Networks

1. Vermont-Oxford Neonatal Network
2. NICHD Development Neonatal Research Network
3. Canadian NICU Network
4. Australian-New Zealand Neonatal Network
5. National networks: Austria, Italy, Spain, Portugal, Norway
6. Regional Networks in many regions, cities....

However, there is no European-wide Neonatal Network
EuroNeoStat projet. Basic facts

- **Financed:** 2005 DG SANCO´s call (6FW program) (€1.0. 60%)
- **Aim:** to develop indicators & collect data(>3.000 DS/y)
- **Starting date:** Jan. 1st 2006 (No real money yet!)
- **Partners:** >30 from >20 European countries
- **Meetings:** Three: Bilbao, Prague & Barcelona
- **Background:** link to EuroNeoNet (a previous iniciative):
  - QC improvememt actions
  - Virtual learning enviroment (Leonardo da Vinci)
  - Clinical trials network
- **Details on worksite:** [www.euroneostat.org](http://www.euroneostat.org) (under construction)
Lists of associated partners

PI: Adolf Valls-i-Soler, JI Pijoán, Bilbao, Spain

Associated partners:
1. Germany: H. Hummler, Ulm
2. Finland: M. Hallman, Oulu
3. France: O. Claris, Lyon (President ESN)
4. Italy: C. Corchia and M. Cuttini, Roma
5. Italy: V. Carnielli, Ancona
6. Norway: T. Stiris, Oslo (President ESPR)
7. Spain: CR. Pallás and Javier de la Cruz, Madrid
8. Sweden: G. Sedin, Uppsala
9. The Netherlands: H. Molendijk, Zwöle
10. UK: H. Halliday, Belfast
11. UK: M. Weindling, Liverpool
Lists of collaborating partners

1. Austria: Berndt Urlesberger, Graz
2. Belgium: Bart Van Overmeire, Antwerp
3. Czech Republic: Richard Plavka, Prague
4. Greece: Marietta Xanthou, Athens
5. Hungary: Dr. Miklos Szabó, Budapest
6. Ireland: Tony Ryan, Cork
7. Poland: Janusz Gadzinowski, Poznan
8. Portugal: Daniel Virella, Lisboa, PSN
9. Romania: Florin Stamatian, Cluj Napoca
10. Slovakia: Darina Chovancova, Bratislava
11. Switzerland: Hans U Bucher, Zurich
12. Russia: Lyubimenko Viacheslau, S. Petersbourg
13. Turkey: Rahmi Örs, Erzurum
14. UK: Mike Hall, Southampton
EuroNeoStat Project 2005-2008
Strategic aim

To develop an I.S. to assess quality of care delivered to very prematurely infants (BW <1.501 g or <32 wks) in Europe, to contribute to the improvement health status of those high-risk infants, and detect any outcome inequalities that might exist.

Mission

Each infant should ideally have the same outcome, no matter at what hospital, region or country is born.
Specific aims

1) Create/validate set of standardised perinatal indicators:
   - To evaluate GA-specific rates of neonatal and post-neonatal morbidity & mortality in VLBW Infants
   - To be used by NICUs for benchmarking to:
     . identify areas with opportunities to improve QC
     . monitor success in doing this efforts

2) To assess clinical variability among NICUs:
   - perform inter-regional comparisons to identify outcomes affected by variability of clinical practices and health delivery systems
Specific aims

3) To test if **GA is a better indication than BW** for both, short- and long-term morbidity & mortality risks

4) To develop / validate a **minimal follow-up dataset** to assess GA-specific health status at 24 month (collaboration with EuroPeriStat II) + expanded questionnaire tested at selected sites

5) To assess **predictive value perinatal indicators** for GA-specific health status at 24 months

6) To develop **software/tools** to collect/transfer/validate/compare perinatal & follow-up data, by use of up-to-date CIT via Internet
• Proposal for a multicenter quality and safety initiative in European Neonatal Intensive Care Units, coordinated by EuroNeoNet

Voluntary reporting systems of near-incidents

• Coordinators: Adolf Valls-i-Soler (Bilbao), Harry Molendijk (Zwolle)
Work packages

- WP-1,2,3: Coordination, Dissemination, Evaluation
- WP-4: Neonatal Morbidity Indicators
- WP-5: Standardized comparison morbidity indicators
- WP-6: Minimal Follow-up dataset
- WP-7: Outcome research: - Outcome variability
  - GA vs. BW as predictors
- WP-8: “EuroNeoSafe”: A patient safety initiative
- WP-9: Software and website
EuroNeoNet Initiative

. Data extraction:
  - Self-obtained reports, via Internet from Web-site:
    - standardised
    - self-designed
  - Comparisons to:
    - All units, national units
  - According to password profile
    - individual units
    - regional level (regional networks)
    - national level (national networks)
Bilbao Coordinating Office (BCO)

- Hospital Cruces:
  - A. Valls i Soler (Neonatologist)
  - J.I. Pijoán (Epidemiologist)

- Basque Institute of Biomedical Research / BIOEF:
  - G. Artola (Project manager)

- Personnel (Part time):
  - Administrator
  - Secretary
  - Data Manager
  - Statistician
Care Assessment

-TASA EMBARAZO MULTIPLE-

-ESTANDARIZACIÓN INDIRECTA SFTTO-

Cruces NICU
Bilbao
Care Assessment

-ESTANDARIZACIÓN INDIRECTA MORTALIDAD-

-Cruces NICU Bilbao-

-ESTANDARIZACIÓN INDIRECTA SEPSIS TARDÍA-
EuroNeoStat projet. Summary

- **Financed:** 2005 DG SANCO’s call (6 FWP) (€1.0; 60%)
- **Aim:** Improve health status VLBWI (as indicator Perinatal care)
- **BCO:** Structure set, personal selected:
  - P manager, dataadministrator, Informatics, Biostatistician
- **Dataset:** 2007 Items & Definitions approved (80 items)
- **1st dataset:** by end 1st trimester 2007 (long hospital stay)
- **Partners:** Increase N units and regional/national networks
- **Sustainability:** Link to ESPR/ESN (Clinical epidemiology)
- **Details on worksite:** [www.euroneostat.org](http://www.euroneostat.org) (under construction)