eurocat
european surveillance of congenital anomalies

EUROCAT Joint Action 2011-2013

Funded by the Public Health Programme 2008-2013 of the European Commission

WHO Collaborating Centre for the Surveillance of Congenital Anomalies

University of ULSTER

Health Programme 2008-2013 Together for Health

Executive Agency for Health and Consumers

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General Objective: To facilitate the reduction of the public health burden of congenital anomalies (CA) by epidemiological surveillance through the EUROCAT network of population-based congenital anomaly registries.

EUROCAT Network: The European Surveillance of Congenital Anomalies (EUROCAT), funded by the European Union and in existence since 1979, is a network comprising almost all of the population based congenital anomaly registries in Europe. It currently surveys more than 1.7 million births per year in Europe, covered by 38 registries in 21 countries. Cases of all major structural congenital and chromosomal anomalies among livebirths, stillbirths and terminations of pregnancy for fetal anomaly , are registered using multiple sources of information. Using common software, each member registry transmits a standard dataset to a central database at EUROCAT Central Registry, where further quality validation is performed.

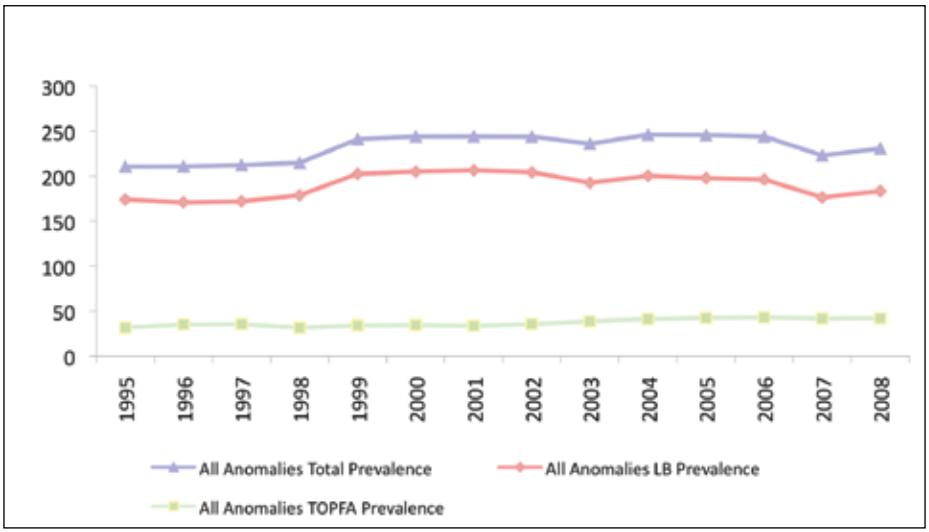

Figure. Prevalence rates (per 10,000 births) for all anomalies, live births (LB) and terminations of pregnancy for fetal anomaly (TOPFA), EUROCAT full member registries, 1995-2008

Source: EUROCAT Website Database: http://www.eurocat-network.eu/ACCESSPREVALENCEDATA/PrevalenceTables (data uploaded 12/04/2011)

Anomaly	LB N	FD N	TOPFA N	LB +FD+TOPFA N	Total prevalence*
Neural tube defects	871	164	2470	3505	10.05
Congenital heart defects	22120	442	2320	24882	71.38
Orofacial clefts	4664	85	568	5317	15.25
Gastroschisis	862	36	131	1029	2.90
Congenital hydronephrosis	3438	30	180	3648	10.47
Hypospadias	5376	8	46	5430	15.80
Club foot	2982	99	372	3454	9.91
Down syndrome	3396	173	3790	7359	21.11
Genetic syndromes	1661	45	298	2004	5.75
Total	66285	1697	14701	82683	237.19

Table. Numbers registered and prevalence of selected congenital anomalies (per 10,000 births) in European countries** 2004-2008

Data accessed at:
http://www.eurocat-network.eu/ACCESSPREVALENCEDATA/PrevalenceTables (11-03-2011)

* Total prevalence includes livebirths (LB), stillbirths and fetal deaths from 20 weeks gestation (FD), and TOPFA (any gestational age).

**for regions covered in each EUROCAT country see http://www.eurocat-network.eu/ABOUTUS/MemberRegistries/CoverageofEuropeanPopulation/PopulationTableI

Regions included in the Table are full member registries

The principal expected outcomes of the EUROCAT Joint Action 2011-2013

1. Evaluation of the public health impact of CA is enabled by easily accessible and updated epidemiological information on the EUROCAT website (www.eurocat-network.eu). The website provides data on prevalence and specific public health indicators for CA, such as perinatal mortality, prenatal detection rates and termination of pregnancies due to severe CA, Down syndrome live birth prevalence, total prevalence of Neural Tube Defects (NTD) and paediatric surgery for CA.

2. The detection, appropriate investigation and reporting of clusters and trends in CA prevalence, including improving the capacity for rapid response through a newly established ***Task Force for Evaluation of Clusters*** in situations demanding immediate actions.

3. Assessment of the teratogenic impact of new or changing environmental exposures, including swine flu related exposures and maternal chronic diseases such as mental depression, obesity, epilepsy, diabetes and asthma.

4. Evaluation of the potential for linkage between databases and electronic information systems on exposure, including European environmental pollution information systems and drug prescription databases in order to enable Europe-wide surveillance and etiological analyses of congenital anomaly risk in relation to such exposures.

5. Establishing strategic framework for primary prevention of CA to be implemented in the national plans for rare diseases.

6. Evaluation of progress in the prevention of NTD in Europe by raising periconceptional folic acid status in women of childbearing age.

7. Evaluation of impact of delayed childbearing and changes in prenatal screening techniques and policy on Down syndrome in Europe.

8. Contribute to the development of a pharmacovigilance system in Europe (***EUROmediCAT***).

9. Improved coding and classification of CA by training in coding and contribution of EUROCAT expertise to the revision of the International Classification of Disease.

10. The addition of ***new registries*** to the network, and provision of guidelines and software to further interested regions/countries.

11. Organisation of two ***European Symposia on the Prevention of Congenital Anomalies*** in order to bring together public health professionals, clinicians, scientists, patient organisations and government agencies and share the latest scientific and clinical results on the monitoring and prevention of CA.

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Members of Project Management Committee

Steering Committee of Elected Registry Leaders

- Lorentz M Irgens (Norway), President of the EUROCAT Association
- Eliza Calzolari (Italy)
- Martin Haeusler (Austria) *until June 2011*
- Babak Khoshnood (France)
- Vera Nelen (Belgium) *until June 2011*
- Diana Wellesley (UK)

Workpackage leaders

- WP1 – Coordination: Helen Dolk (UK: Project Leader)
- WP2 – Dissemination: Ingeborg Barisic (Croatia)
- WP3 – Evaluation (subcontracted to Ulster)
- WP4 – Registration, central database and surveillance: Maria Loane (UK)
- WP5 – Coding and classification, and data quality: Ester Garne (Denmark)
- WP6 – Investigation of trends, clusters and new exposures : Martine Vrijheid (Spain)
- WP7 – Primary prevention: Domenica Taruscio (Italy)
- WP8 – Prenatal screening, Down Syndrome, and genetic syndromes: Joan Morris (UK)
- WP9 – Medication during pregnancy: Marian Bakker (The Netherlands)

EUROCAT Project Leader

Helen Dolk,
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Strategic Relevance: CA are a major group of mainly rare diseases where concerted action across Europe has been identified as a priority in the Council Recommendation of 8 June 2009 on an action in the field of rare diseases, and in the Communication from the Commission on Rare Diseases: Europe's challenges of November 2008.

These recognise the need for registries and databases co-ordinated at a European level, for pooling of expertise, improving the coding and classification of rare diseases, for comparable epidemiological data at EU level, and for identifying the possibilities for primary preventive measures.

This Joint Action combines funding of the EU and member states (MS) in order to secure a sustainable, high quality and easily accessible information system on congenital anomalies for almost one third of the European birth population. The results of the EUROCAT Joint Action 2011-2013 are expected to have an important impact on future MS policy on rare diseases.

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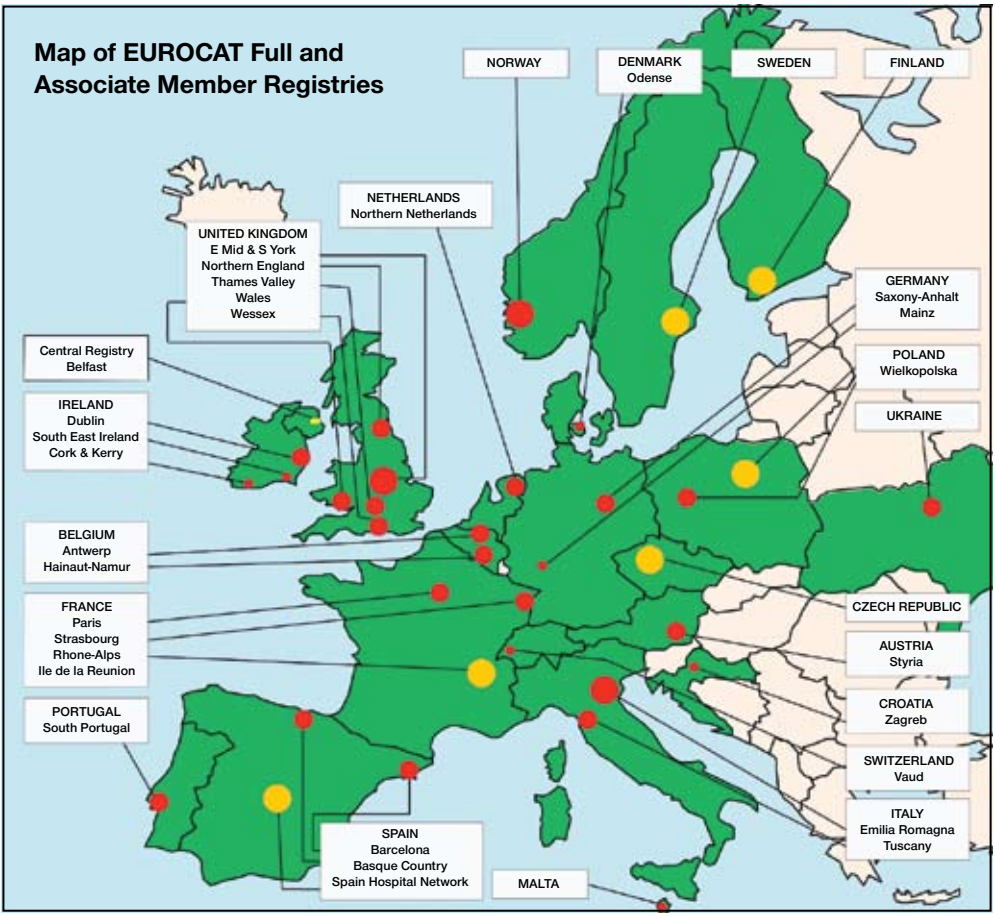

Full member

Associate member

Size of circles

<10,000 births per year

10,000-40,000 births per year

>40,000 births per year