

Presentation of Latest EUROCAT Data on Neural Tube Defects

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EUROCAT Central Registry Project Manager

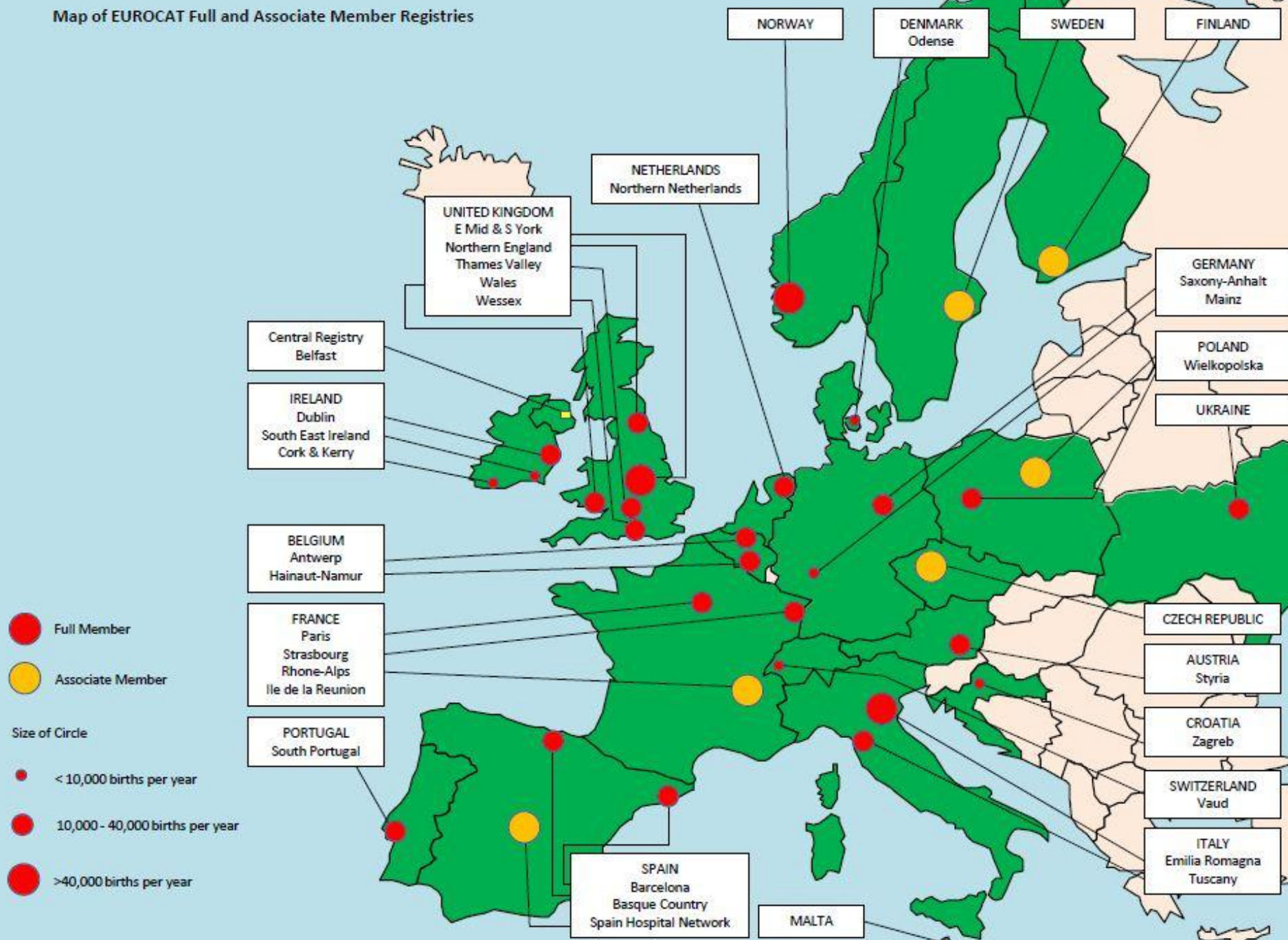
Brussels, 29 June 2011



About EUROCAT

- **EUROCAT:** The European Surveillance of Congenital Anomalies (CA)
- In existence since 1979
- A network comprising almost all of the population-based registries for the epidemiological surveillance of CA in Europe
- Currently surveys more than 1.7M births per year in Europe (31% of birth population covered in the EU via 38 registries in 21 countries)
- Cases of all major structural congenital and chromosomal anomalies among livebirths (LB), still births (SB) and terminations of pregnancy for fetal anomaly (TOPFA) following prenatal diagnosis (PND), are registered using multiple sources of information
- Using common software, each member registry transmits either anonymised individual case data (full members) or summary data (associate members) to a central database at EUROCAT Central Registry, where further quality validation is performed

Map of EUROCAT Full and Associate Member Registries



About EUROCAT

- **General Objective:** To facilitate the reduction of the public health burden of CA by epidemiological surveillance through the EUROCAT network of population-based CA registries
- **WHO Collaborating Centre for the Surveillance of CA**
 - To assist the WHO in implementing the resolution WHA63.17 of the 63rd World Health Assembly (2010) on birth defects
- www.eurocat-network.eu

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Announcements [[Archive Announcements](#)]

11th EUROCAT Symposium on Prevention of Congenital Anomalies (17 June 2011) and 26th Registry Leaders Meeting (15-16 June 2011) in Antwerp, Belgium

Details about the EUROCAT Symposium can be found on www.eurocat2011.com. Please note that the deadline for Abstracts is 15 April 2011.

The details of the hotel are as follows:

Lindner Hotel City Lounge, Lange Kievitstraat 125, 2018 Antwerp, Belgium

Tel: +32 3 22 777 00

Fax: +32 3.22 777 01

Email: info.antwerpen@lindnerhotels.be

New Publication - Dolk H, Loane M, Garne E and a EUROCAT Working Group, "Congenital Heart Defects in Europe: Prevalence and Perinatal Mortality, 2000-2005" (2011), *Circulation*, Vol 123, pp 841-849 [<http://circ.ahajournals.org>]

The paper describes the prevalence of Congenital Heart Defects (CHD), diagnosed prenatally or in infancy, and fetal and perinatal mortality associated with CHD in Europe. Data were extracted from the European Surveillance of Congenital Anomalies central database for 29 population-based congenital anomaly registries in 16 European countries covering 3.3 million births during the period 2000 to 2005. On the basis of this analysis we estimate that annually in the European Union, 36 000 children are live born with CHD and 3000 who are diagnosed with CHD in utero or at birth die as a terminations of pregnancy following prenatal diagnosis, late fetal death, or early neonatal death. Investing in primary prevention and pathogenetic research is essential to reduce this burden, as well as continuing to improve cardiac services from in utero to adulthood

"EUROCAT receives funding from the European Union, in the framework of the Public Health Programme"

"EUROCAT is a WHO Collaborating Centre for the Epidemiology Surveillance of Congenital Anomalies"

"EUROCAT Central Registry is based at the University of Ulster"

EUROCAT Joint Action (JA) 2011-2013

- EUROCAT is currently funded as a JA of the EU and Member States (MS) through the DG Sanco Public Health Programme
- **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 8th 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 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
- The JA combines funding of the EU MS in order to secure a sustainable, high quality and easily accessible information system on CA for almost one third of the European birth population
- Through the JA EUROCAT expects to have an important impact on future MS policy on rare diseases

Principal Expected Outcomes of the EUROCAT JA 2011-2013

4 of 11 Relate directly to NTDs

- Evaluation of the public health impact of CA is enabled by easily accessible and updated epidemiological information on the EUROCAT website
- Strategic framework for primary prevention of CA to be implemented in the national plans for rare diseases
- Evaluation of progress in the prevention of NTD in Europe by raising periconceptual folic acid (FA) status in women of childbearing age
 - Monitor total prevalence
 - Establish a protocol to monitor folate status in the pregnant population
- Organisation of 2 **European Symposia on the Prevention of CA** 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

EUROCAT Project Leader - Helen Dolk (UK)

Steering Committee of Elected Registry Leaders

- Lorentz Irgens (Norway), President of the EUROCAT Association
- Eliza Calzolari (Italy)
- Ingeborg Barisic (Croatia)
- Babak Khoshnood (France)
- Carmen Martos (Valencia)
- Diana Wellesley (UK)

9 Workpages

- WP1 - Coordination (Helen Dolk, UK)
- WP2 - Dissemination (Ingeborg Barisic, Croatia)
- WP3 - Evaluation (Helen Dolk, UK)
- 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)

What does EUROCAT monitor about NTDs and why?

- Birth defects registries are vital to monitor the impact of strategies to raise FA status of women periconceptionally in order to prevent NTDs
 - The total prevalence measure is used to track progress in primary prevention
 - Total prevalence of NTDs includes LB with a NTD, SB and foetal deaths from 20 wks gestation with a NTD, and TOPFA (with an NTD)
- The LB prevalence measure includes only LB. The LB measure is used to inform EU MS regarding the need to provide high quality health and other services for children living with a NTD and their families

Special Report: Special Report:

Prevention of Neural Tube Defects by Periconceptional Folic Acid Supplementation in Europe

(Updated version December 2009)

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EUROCAT receives funding from the European Union, in the framework of the Public Health Programme
WHO Collaborating Centre for the Epidemiology Surveillance of Congenital Anomalies



- Every few years, EUROCAT updates the EUROCAT Special Report on Prevention of NTD by FA

- Published in scientific journals

- The latest edition (2009) includes a policy survey of European countries, and detailed presentation of prevalence data for each country

<http://www.eurocat-network.eu/PREVENTIONAndRISKFACTORS/FolicAcid/FolicAcidSpecialReports>

- Previous copies are retained on the website for comparison

EUROCAT Registered Data Between 2004-2008 – used for the 2nd Report

- 35 registries
- 18 countries
- During this time period EUROCAT had a total coverage of 4.1 Million births across these registries
- This relates to a total of 3987 NTD registrations

EUROCAT Registered Data on NTDs for the 2nd Report

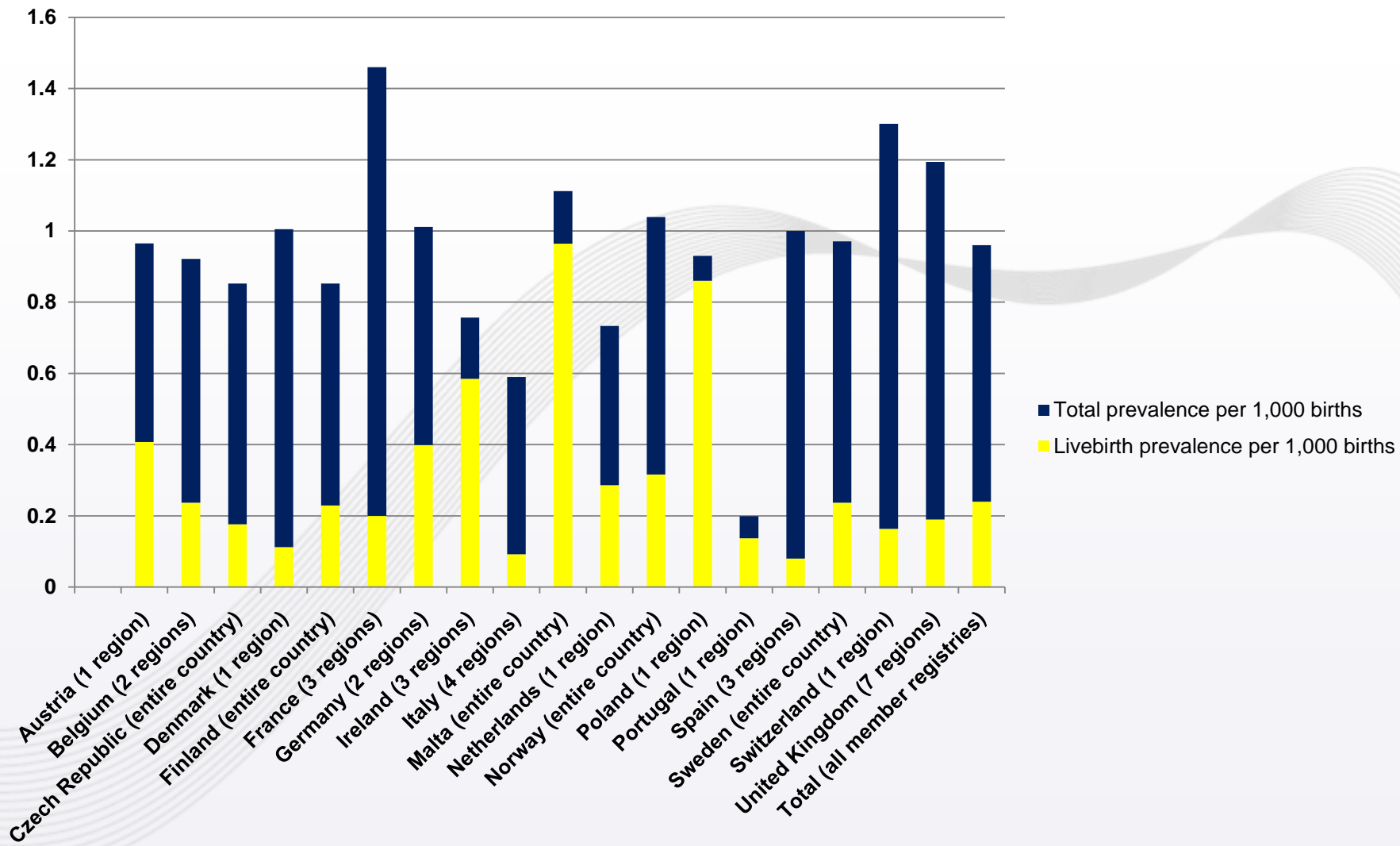
Overview

- The total prevalence of NTDs in Europe, between 2004 and 2008, was 0.96 per 1,000 births
- The LB prevalence in Europe, between 2004 and 2008, was 0.24 per 1,000 births
- The discrepancy between LB and total NTD prevalence is mainly explained by TOPFA following PND of NTD
- Over 4,500 pregnancies are affected by a NTD every year in Europe. Between 2004 and 2008 recorded data shows that an estimated 72% of these pregnancies were terminated following PND
- Within all NTDs the total prevalence for Spina Bifida in Europe, looking at data from 2004 to 2008, was 0.5 per 1,000 births
- The LB prevalence for Spina Bifida in the same period was 0.9 per 1,000 births

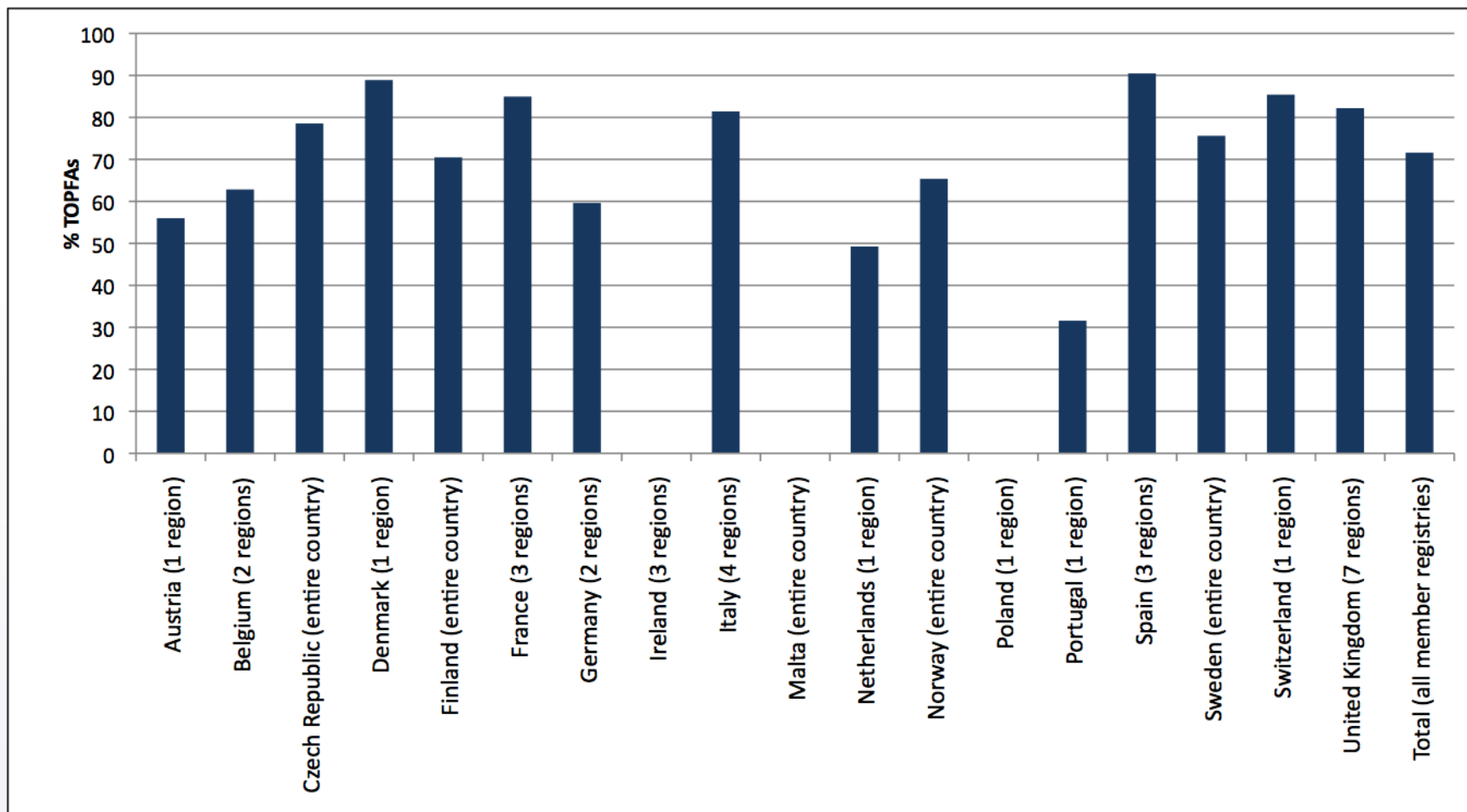
Prevalence of Neural Tube Defects (per 1,000 births) in European countries 2004-2008: EUROCAT data

Anomaly registry	Year Range	Livebirth prevalence per 1,000 births	Total prevalence*** per 1,000 births
Austria (1 region)	2004 - 2008	0.41	0.97
Belgium (2 regions)	2004 - 2008	0.24	0.92
Czech Republic (entire)	2004-2007	0.18	0.85
Denmark (1 region)	2004 - 2008	0.11	1.01
Finland (entire country)	2004-2006	0.23	0.85
France (3 regions)	2004 - 2008	0.2	1.46
Germany (2 regions)	2004 - 2008	0.4	1.01
Ireland (3 regions)	2004 - 2008	0.58	0.76
Italy (4 regions)	2004 - 2008	0.09	0.59
Malta (entire country)	2004 - 2008	0.96	1.11
Netherlands (1 region)	2004 - 2008	0.29	0.73
Norway (entire country)	2004 - 2006	0.32	1.04
Poland (1 region)	2004 - 2008	0.86	0.93
Portugal (1 region)	2004 - 2008	0.14	0.2
Spain (3 regions)	2004 - 2008	0.08	1
Sweden (entire country)	2007-2008	0.24	0.97
Switzerland (1 region)	2004 - 2008	0.16	1.3
United Kingdom (7 regions)	2004 - 2008	0.19	1.19
Total (all member registries)	2004 - 2008	0.24	0.96

Prevalence of Neural Tube Defects (per 1,000 births) in European countries 2004-2008: EUROCAT data



Proportion* of Neural Tube Defect** cases resulting in termination of pregnancy in European countries*** 2004-2008: EUROCAT data



Data accessed at <http://www.eurocat-network.eu/ACCESSPREVALENCEDATA/PrevalenceTables> (05-01-2011)

*Number of cases of termination of pregnancy of NTD as a percentage of all NTD cases (liveborn or stillborn/fetal death from 20 weeks gestation or TOPFA). Note that the proportion of cases prenatally diagnosed for anencephaly and spina bifida (regardless of pregnancy outcome) can be found at:

<http://www.eurocat-network.eu/PRENATALSCREENINGAndDIAGNOSIS/PrenatalDetectionRates>.

**including anencephaly, spina bifida, encephalocele

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

Regions included in the Figure are full member registries and associate member registries in countries where there are no full member registries

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Access Prevalence Tables

If you would like to interrogate the database further
to your own specifications, please



Continue ▶



Some example tables:

PDF Version [Table "Prevalence 96 Subgroups Last 5 years"](#)

PDF Version [Table "Down Syndrome Last 5 Years"](#)

The results generated here are in PDF format and you will need an appropriate application installed to view them.
You can click on the icon below to install the Adobe Reader.



What does the EUROCAT data on NTDs tell us?

- As EUROCAT's Special Reports show, there has been no real progress in preventing NTDs in Europe for the 15 yrs since an MRC randomised trial of periconceptual FA supplementation showed this to be an effective preventive measure. Instead, NTD prevalence has remained relatively stable
- Low total prevalence rates of NTD may indicate
 - Better FA/vitamin status through supplementation and/or voluntary food fortification and diet
 - A lesser genetic predisposition for NTD
 - Incomplete data

EUROCAT Recommendations

- Consider in the context of the **[National Plans]**

1. European countries could prevent most NTDs in planned pregnancies by putting in place an official policy recommending periconceptional FA supplementation and taking steps to ensure that the population are aware of the benefits of supplementation and the importance of starting supplementation **before** conception
2. European countries should review their policies regarding FA fortification and supplementation taking into account available information on benefits and hazards of both. They should pay special attention to results of studies done post mandatory fortification in countries that have introduced it
3. As many pregnancies are unplanned, European countries could achieve more effective prevention of NTDs by additionally introducing fortification of a staple food with FA. The particular objectives of this policy would be preventing NTDs among women who do not plan their pregnancy, and reducing socio-economic inequalities in NTD prevalence

EUROCAT Recommendations

4. Health effects of supplementation and fortification should be monitored, and policies should be reviewed periodically in light of the findings
5. The European population should be covered by high quality CA registers which collect information about affected pregnancies (LB, SB and TOPFA). One important use for the information would be to assess the effect of FA supplementation and fortification on NTD rates as well as rates of other CA

Summary

- Prevalence is still too high
- The importance of registry surveillance
 - The problems associated with incomplete data reinforces the requirement for MS to ensure that their registries are adequately resourced and supported to produce high quality data
- Only very recently do we see a decline in prevalence in some countries. This needs to be monitored further to see if the decline will be sustained. It is part of EUROCAT's mission to bring these problems within health policy and its implementation to the attention of the MS

A decorative graphic consisting of multiple thin, parallel lines that form a wavy, ribbon-like shape across the lower half of the page. The lines are light gray and create a sense of movement and depth.

Thank you