

EUROPEAN COMMISSION

HEALTH AND CONSUMERS DIRECTORATE-GENERAL

Public Health and Risk Assessment **Health information**

NOTE TO HEALTH INFORMATION COMMITTEE

Subject: EUROCAT

EuroCat is the European Network on "Surveillance of congenital anomalies in Europe" (http://www.eurocat-network.eu/index.html).

Under the coordination of the University of Ulster, Northern Ireland (UK), since 2000 in 4 consecutive projects a European network for the epidemiological surveillance of congenital anomalies has been established, currently comprising 51 registries in 28 countries, which in turn surveyed more than 1 million births per year in Europe. Some of the main objectives are to:

Provide essential epidemiological information on congenital anomalies in Europe based on a common dataset with common coding as specified in the EUROCAT Guide and the EUROCAT Data Management Programme (EDMP) used by member registries for data input/import, validation and annual transmission to the Central Registry;

Act as an information and resource centre for the population, health professionals and managers regarding clusters or exposures or risk factors of concern;

Provide a ready collaborative network and infrastructure for research into the causes and prevention of congenital anomalies and the treatment and care of affected children; and

survey policies and practices with regard to peri-conceptional folic acid supplementation.

Recently, EUROCAT updated its report on neural tube defects (NTD) rates in 18 European countries in the context of folic acid policy and practices. The report, available on the EUROCAT website (see above), demonstrates that more countries have begun issuing advice to women to take peri-conceptional folic acid. No country has yet introduced mandatory fortification of food with folic acid, however, although the policy is being advised in several countries. The decline rate in NTD remains disappointing.

In addition, EUROCAT has developed a new website in January 2010 (see above) and is currently working with support from the health program 2008-2013 on a report on European needs and options for post natal screening programs.

Finally, EUROCAT has applied for a Joint action under the Health program call 2009. The joint action application aims at sustaining and extending EUROCAT from 2010 until 2013 with a view to enhance cooperation and support on European surveillance of congenital anomalies within and among the Member States.

The application comprises the following 9 work packages WP1: Co-ordination, WP2: Dissemination, WP3: Evaluation, WP4A: Core registration, database and prevalence data, WP4B: Coding and classification, data quality, WP5: Surveillance – trends, clusters

and investigation of new exposures, WP6: Primary prevention of congenital anomalies, WP8: Prenatal screening and Down Syndrome, WP9: Medication during pregnancy

In addition to the objectives pursued by EUROCAT, as described above, the following new initiatives are covered by the 9 work packages: Creation of a Rapid Response Team, New aspects of Down Syndrome: impact of introduction of non-invasive testing, National plans for primary prevention of congenital anomalies, Strategies for prevention, Pre and peri conceptional care, Folic acid supplementation, Management of epilepsy, diabetes, Smoking, alcohol reduction, Genetic counselling, Whole population approaches, Folic acid fortification and nutrition, Rubella (and other infection) vaccination, Environmental, occupational, pharmaceutical regulation, Tackling major health determinants specifically for pregnancy (obesity, smoking, recreational drugs), Socioeconomic inequalities and migrant health, Investment in RESEARCH into causes and surveillance and environmental/pharmacovigilance, Obesity/BMI inclusion in dataset, Improving data on drugs and environmental exposures by data linkage. The EAHC is currently evaluating the application.

Further reading:

http://ec.europa.eu/health/ph_projects/2001/rare_diseases/rarediseases_project_2001_full_en.htm#1



Action for the Committee:

X	For information
	For comments
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