eurocat
european surveillance of congenital anomalies

EUROCAT Statistical Monitoring Report – 2009

Executive Summary

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WHO Collaborating Centre for the Epidemiology Surveillance of Congenital Anomalies

EUROCAT 2009 Statistical Monitoring of Congenital Anomalies: Key Findings

Reducing the occurrence of congenital anomalies, a leading cause of fetal death, infant mortality and morbidity in childhood, has been identified as one of the key objectives of the WHO Millennium Development Goal 4. Essential to the success of this objective are surveillance systems that systematically monitor epidemiologic data on the rates of birth defects over time.

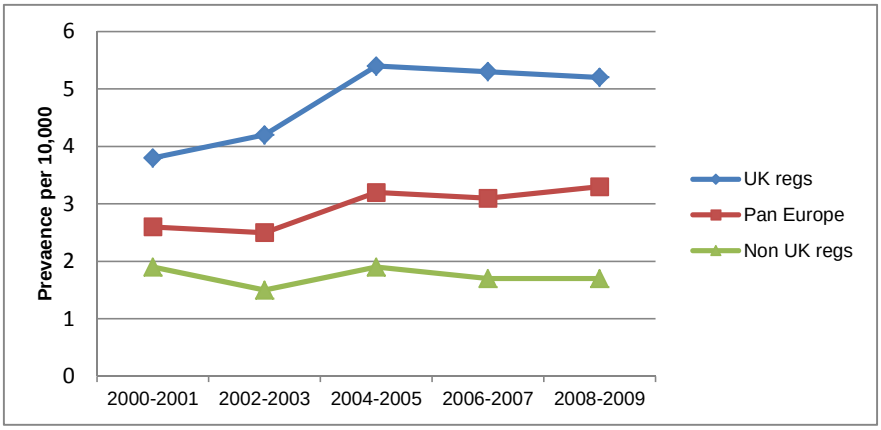
Each year EUROCAT, the European network of population-based registries for the epidemiologic surveillance of congenital anomalies, performs statistical monitoring for both trends and clusters in time in order to detect signals of new or increasing teratogenic exposures and monitor progress in the prevention of congenital anomalies. We monitor total prevalence rates of congenital anomalies, that is, rates which include cases in livebirths, stillbirths, and terminations of pregnancy for fetal anomaly. Before interpreting any increase or decline in total prevalence as a true increase or decline in risk potential diagnostic changes must be considered. In this report 22 EUROCAT regions are included. These regions can find their full results in the main report. Our key findings concentrate on the pan-European analysis, which gives a snapshot of the situation in Europe.

Key findings

Increasing trends

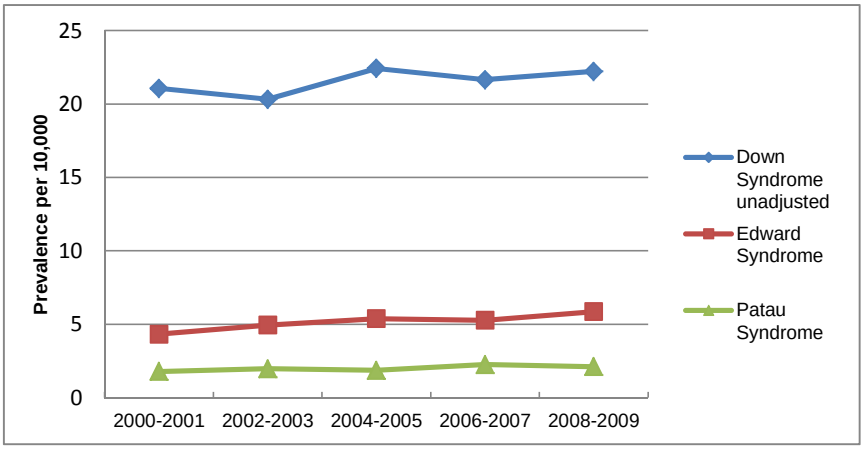
- There has been an increase in the prevalence of **Gastroschisis** by 29%, from 2.56 per 10,000 births in 2000-2001 to 3.30 in 2008-2009.The UK had a higher rate than other countries, increasing in the early part of the decade, and has remained consistently high. Gastroschisis is a rare abdominal defect requiring corrective surgery, associated with factors such as young maternal age, low maternal BMI, maternal smoking and low socioeconomic status.

Prevalence of gastroschisis in pan-Europe analysis



- The prevalence of the three main types of chromosomal trisomy syndromes increased at pan-European level. The prevalence of **Down syndrome/trisomy 21** increased by 5% from 21.07 in 2000-2001 to 22.22 in 2008-2009. Significant increasing trends were also found for **Edward syndrome/trisomy 18**, which increased by 36% from 4.32 per 10,000 in 2000-2001 to 5.86 in 2008-2009 and **Patau syndrome/trisomy 13** which increased by 18% from 1.79 per 10,000 to 2.11 per 10,000 in 2008-2009. Following adjustment for maternal age no increasing trend was found for Down syndrome suggesting that the trend found for this syndrome is associated with increases in the proportion of older mothers. Currently EUROCAT does not adjust for maternal age for Edward and Patau syndrome. In addition to increases in maternal age explanations for increasing trends in these two syndromes could be improvements in prenatal diagnosis.

Prevalence of chromosomal trisomy syndromes in pan-Europe analysis

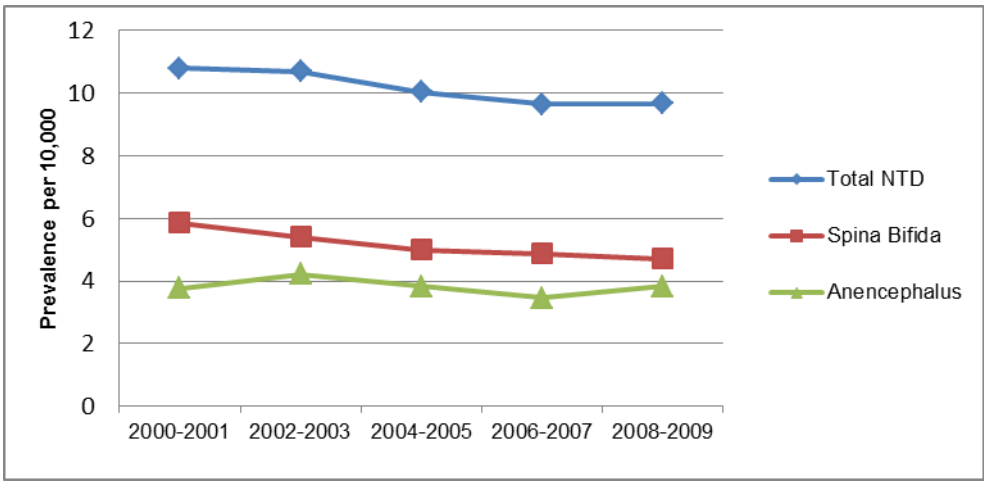


Decreasing trends

Overall, there was a decline in the prevalence of all non-chromosomal anomalies at pan-European level, which included decreasing trends in a range of major anomalies such as neural tube defects and congenital heart defects.

- At pan-European level the prevalence of **neural tube defects** declined by 10% from 10.80 cases per 10,000 in 2000-2001 to 9.67 in 2008-2009. Occurrences of cases with **spina bifida** declined by 19% from 5.86 per 10,000 in 2000-2001 to 4.72 in 2008-2009. There was no significant change in the prevalence of **anencephalus** from 2000-2009. The decreasing trends in neural tube defects and spina bifida suggests that measures to reduce the occurrence of this anomaly, particularly folic acid supplementation and voluntary food fortification, are beginning to have some success. However this decline is relatively small compared to what could be potentially achieved by raising periconceptual folate status for a greater proportion of women.

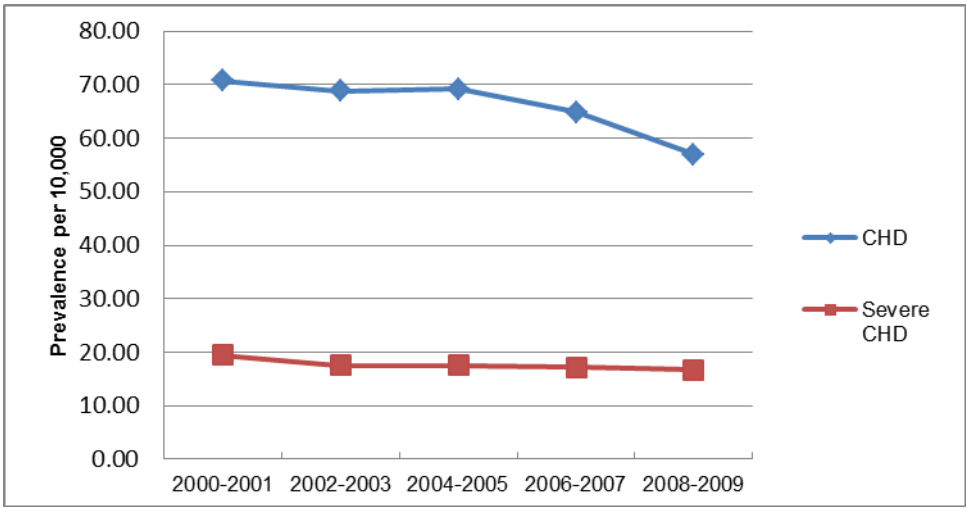
Prevalence of Neural Tube defects in pan-Europe analysis



- Congenital heart defects (CHD) are the most common congenital anomalies, accounting for a third of congenital anomaly cases, and a decline in prevalence is found in the latter part of the decade. The prevalence of **severe CHD** decreased by 14% from 19.49 per 10,000 in 2000-2001 to 16.71 in 2008-2009. Decreasing trends were also observed for specific types of severe CHD as well as ventricular septal

defect and pulmonary valve stenosis. There is growing evidence to suggest that folic acid supplementation may be effective in reducing the risk of CHD. There may also be other explanations such as the improved management of known risk factors such as maternal chronic health conditions e.g. diabetes, and the reduction of health risk behaviours e.g. smoking.

Prevalence of congenital heart defects in pan-Europe analysis



Clusters

Cluster analysis did not identify clusters in 2008-9 thought to be of immediate concern.

Conclusions

The EUROCAT network, now a Joint Action between the European Union and Member States, provides essential surveillance information on congenital anomalies in Europe. The high and increasing prevalence of gastroschisis in the UK continues to need attention. The trend towards delayed childbirth in Europe continues to bring with it an increase in the prevalence of Down syndrome and other trisomy syndromes. However we are pleased to report a decline in prevalence of some major anomalies in the last decade, though much work in primary prevention of congenital anomalies remains to be done. Primary prevention of congenital anomalies should be added to National Plans for Rare Diseases currently under development, to make sure that the entire European population has access to appropriate preventive services and policies.