

SYNNYNÄISET EPÄMUODOSTUMAT SUOMESSA

**CONGENITAL
MALFORMATIONS
IN FINLAND**

Sonja Kiuru-Kuhlefelt



NATIONAL INSTITUTE FOR HEALTH AND WELFARE



Contents

- Finnish Register of Congenital Malformations
- Prevalence of malformations in Finland
- Malformation subgroups



Finnish Register of Congenital Malformations

Epämuodostumarekisteri

- Established in 1963
- Good coverage and quality since 1993
- Monitoring, statistics, reporting, research
- Member of ICBDSR (1974) and EUROCAT (1998)



Finnish Register of Congenital Malformations

- Data sources: hospitals, laboratories, other registries
(Medical Birth Register, Register of Induced Abortions, Care Register for Health Care (HILMO), Statistics on Causes of Death)
- Annually ~ 7000 cases notified, ~ 3200 monitored as "major anomalies"
- Statutory, mandatory notification, no informed consent needed
(Act on Nationwide Health Care Registers, Act on the National Institute for Health and Welfare)



Finnish Register of Congenital Malformations

Malformation notification

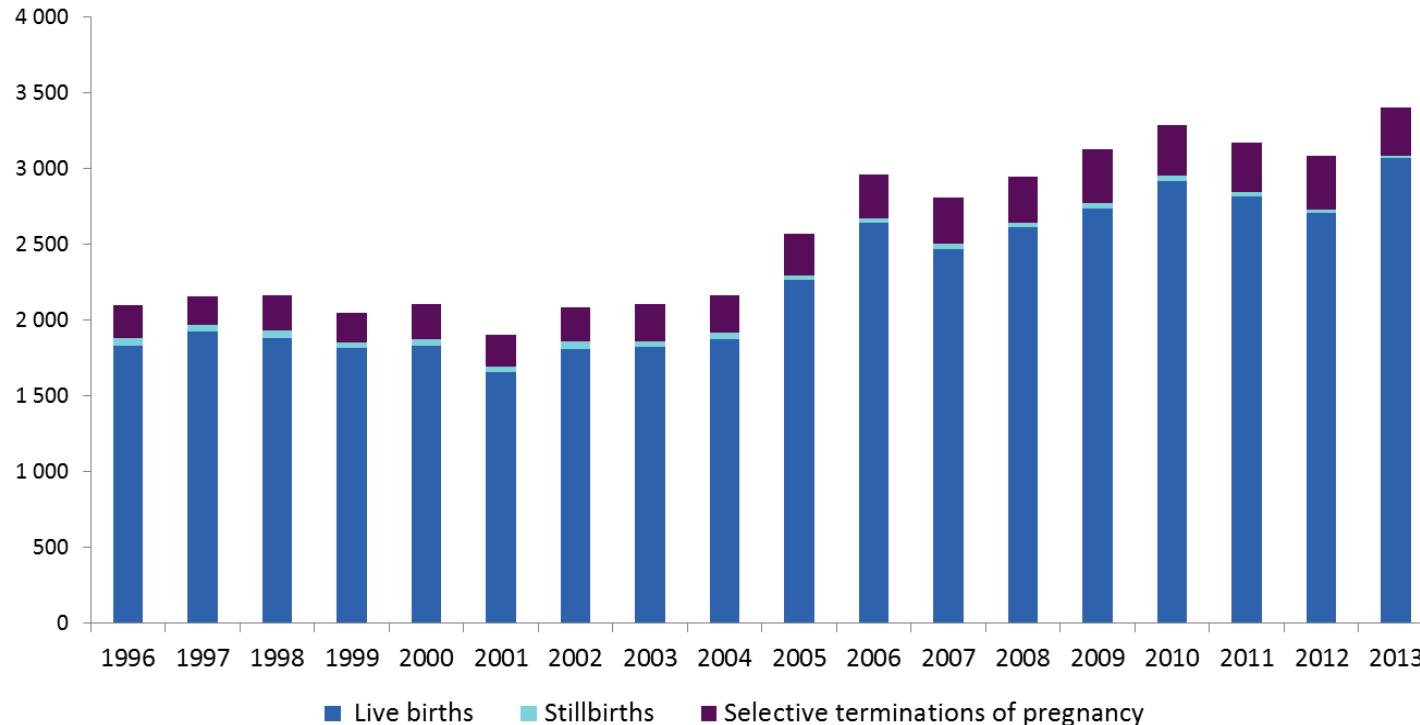
- Mother's and child's complete identification data
- All malformations observed
- Time of detection and performed investigations
- Results of all genetic tests
- Autopsy and other reports
- Contact details of notifier



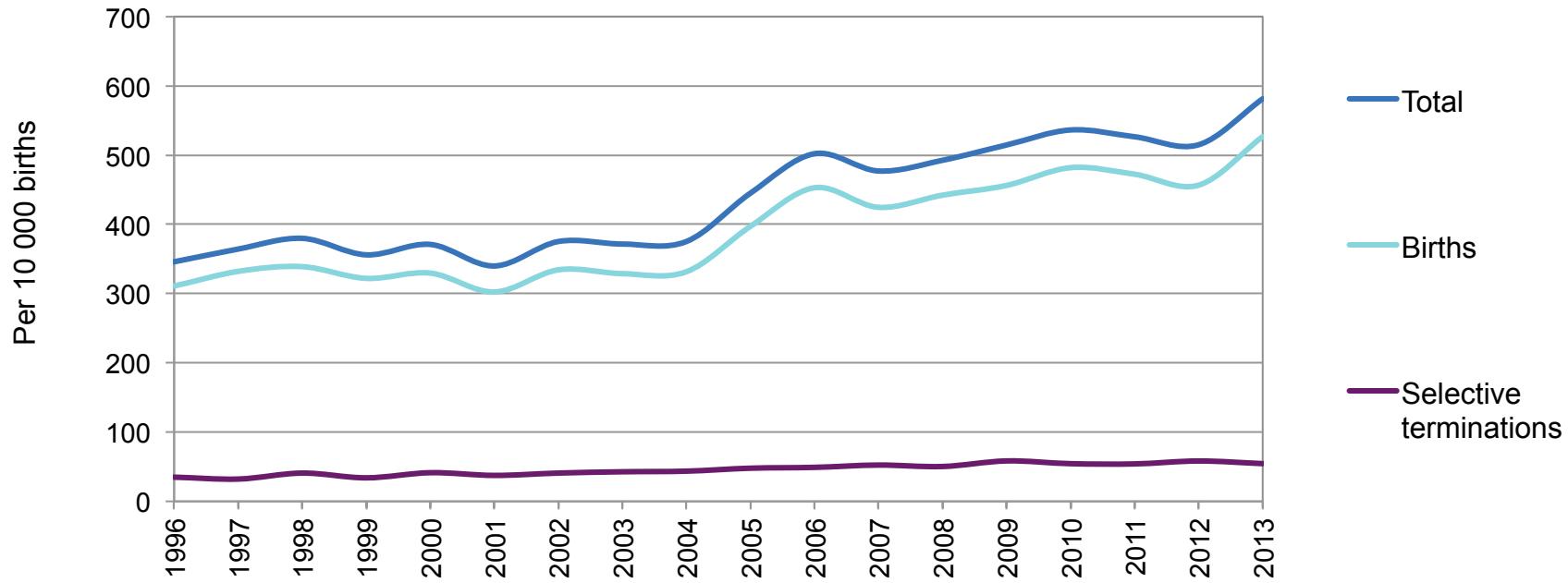
Prevalence of malformations



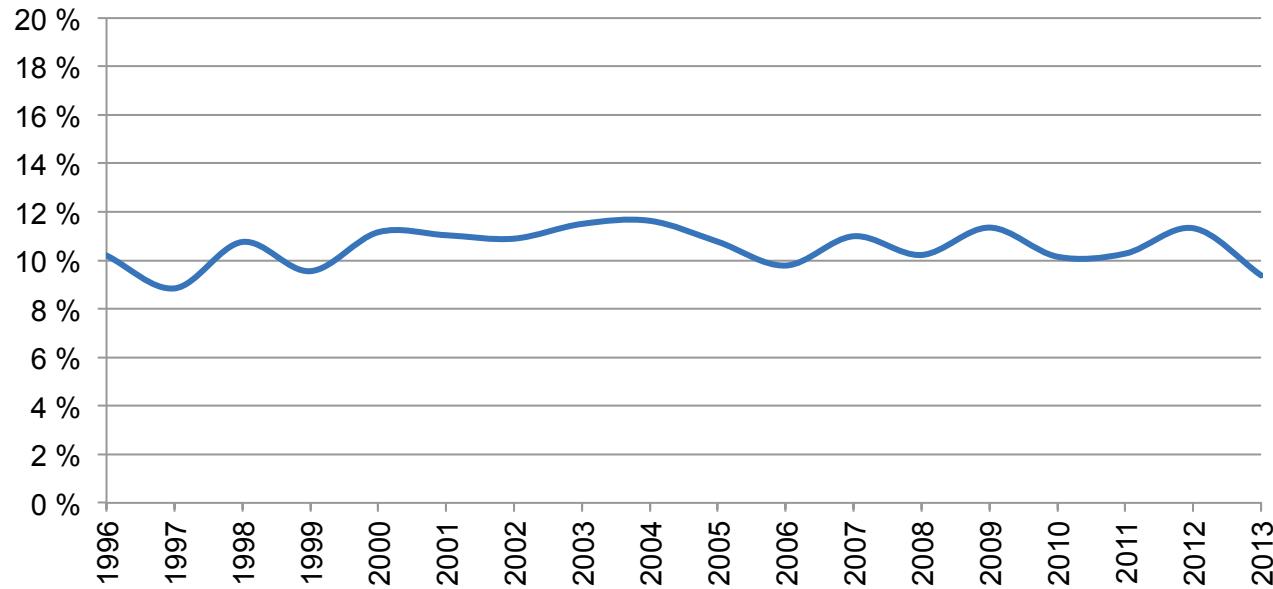
Number of cases with congenital anomalies



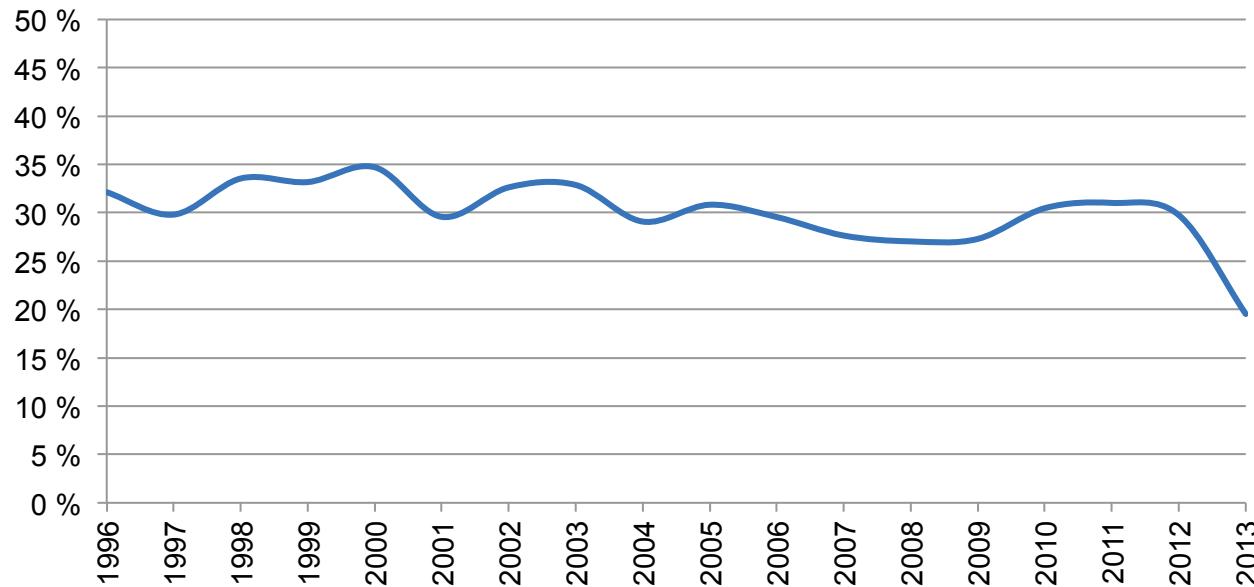
Prevalence of cases with congenital anomalies 1/10 000



Proportion of selective terminations among all cases with major congenital anomalies, %



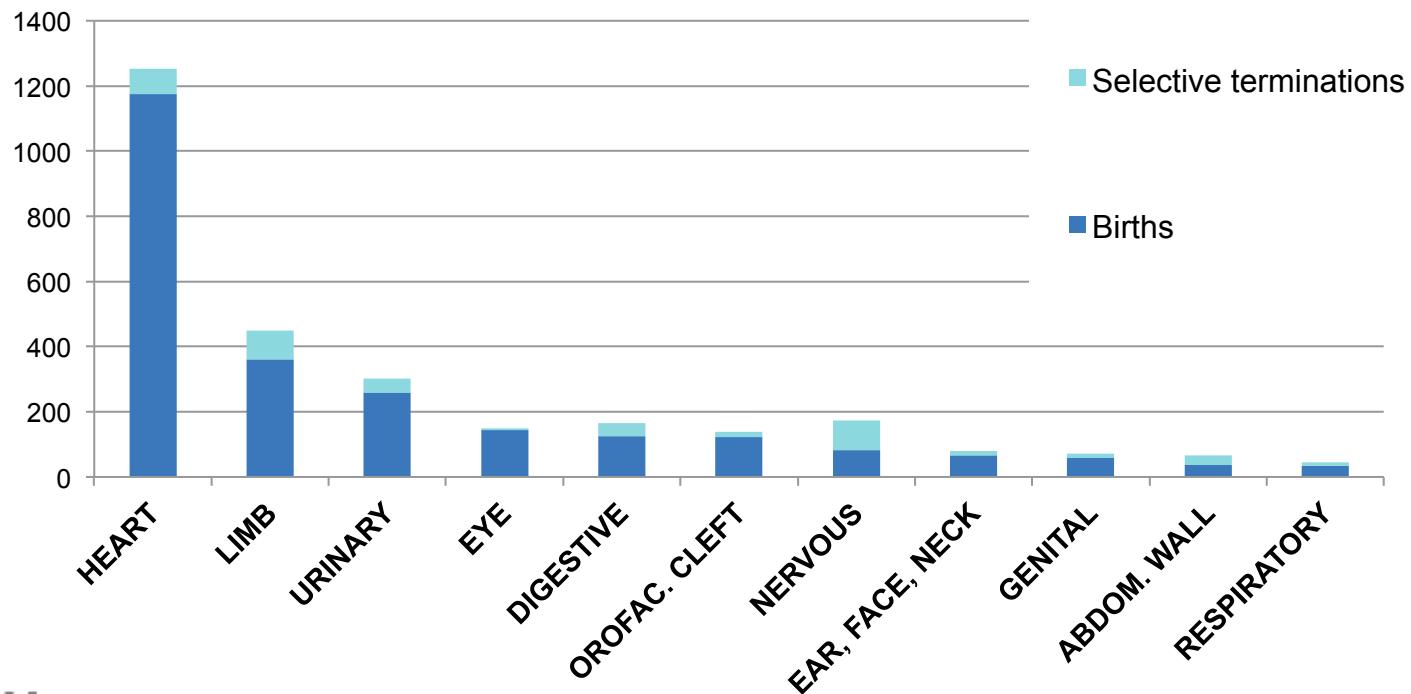
Proportion of congenital anomalies among all stillbirths and infant deaths, %



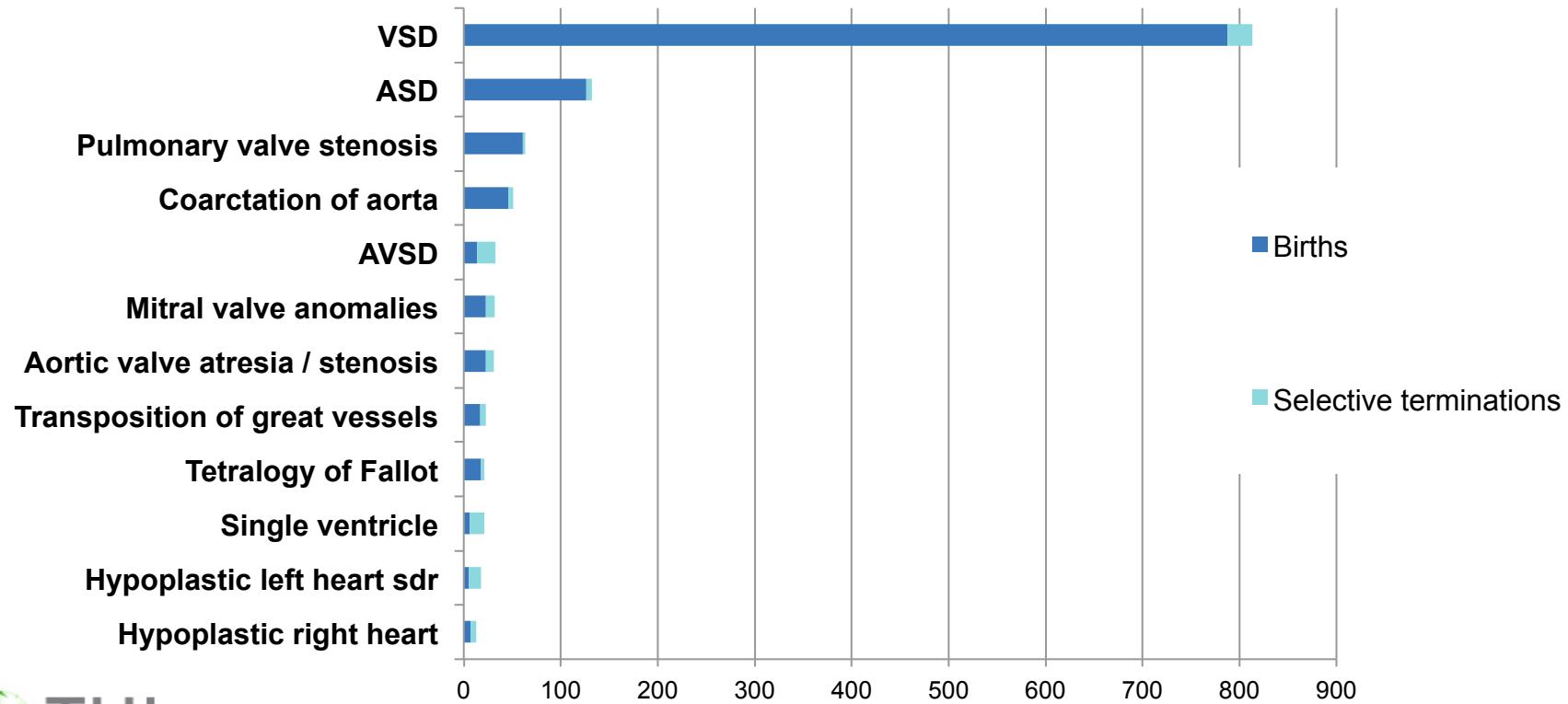
Malformation subgroups



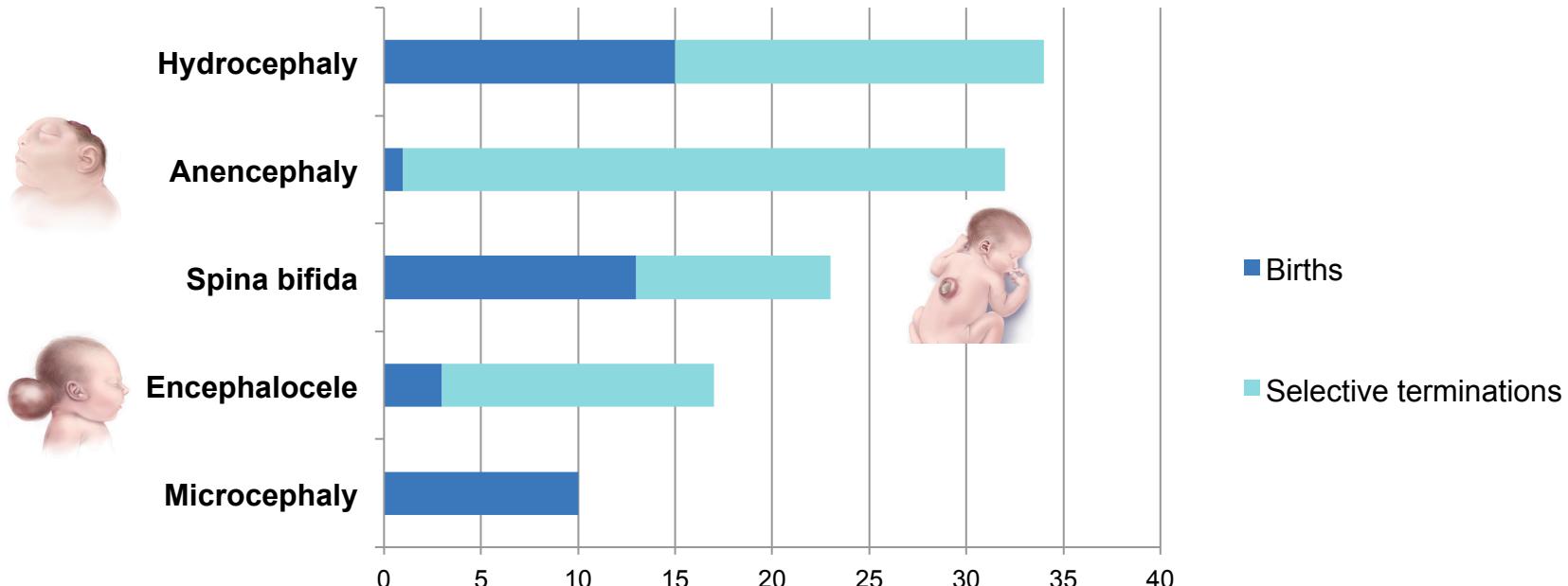
Number of anomalies in major subgroups, year 2012



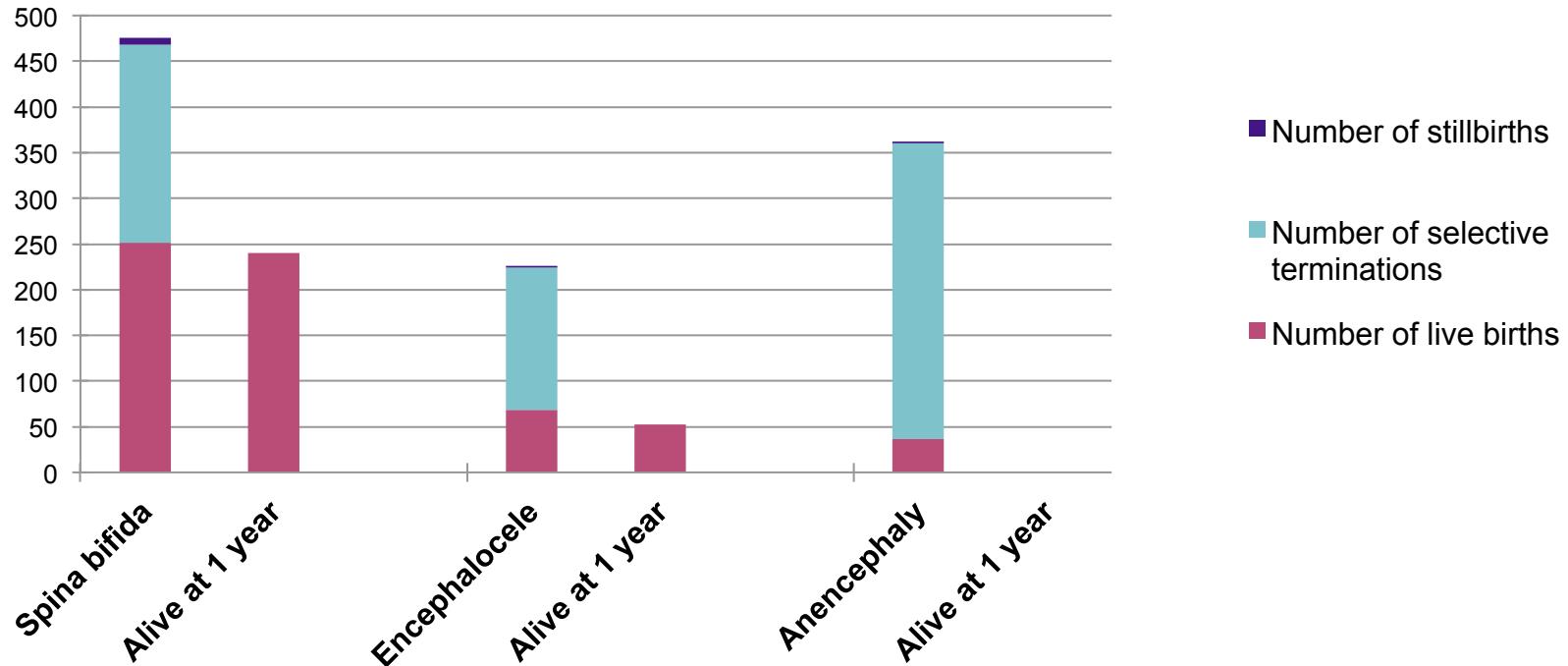
Congenital heart defects, year 2013



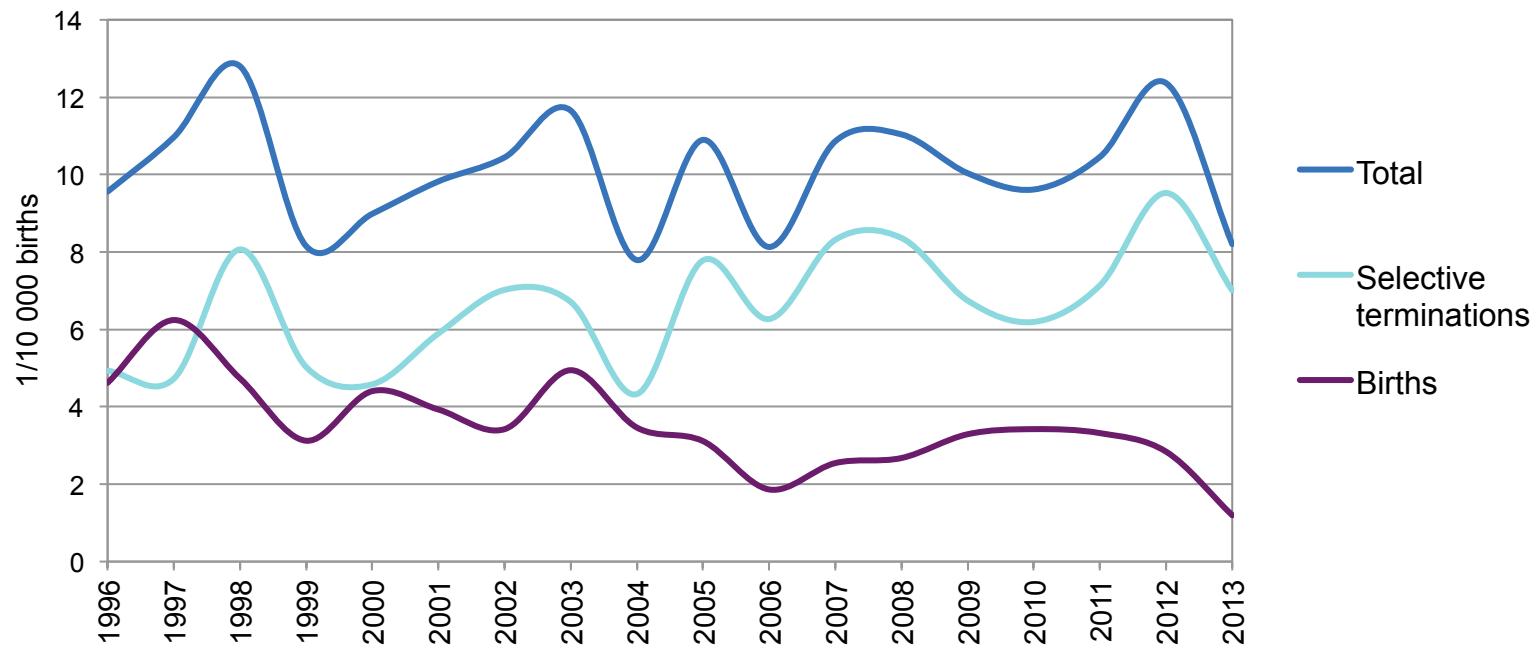
Anomalies of nervous system, year 2012



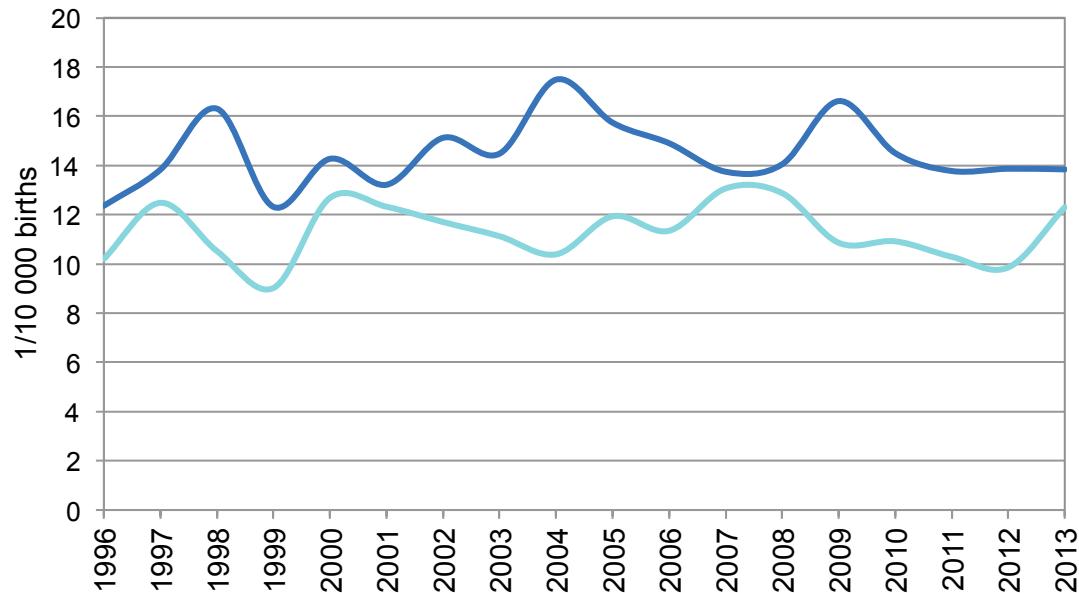
Neural tube defect cases 1996-2013



Prevalence of neural tube defects 1/10 000



Prevalence of orofacial clefts



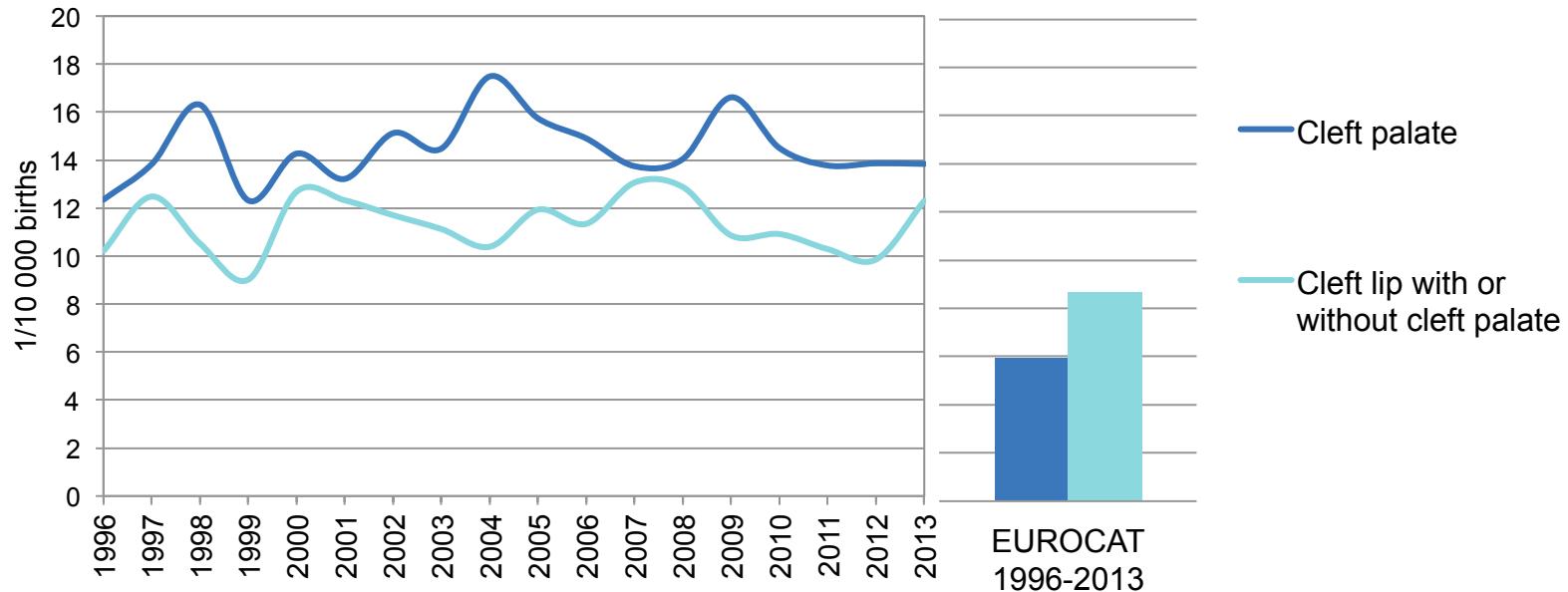
Cleft palate



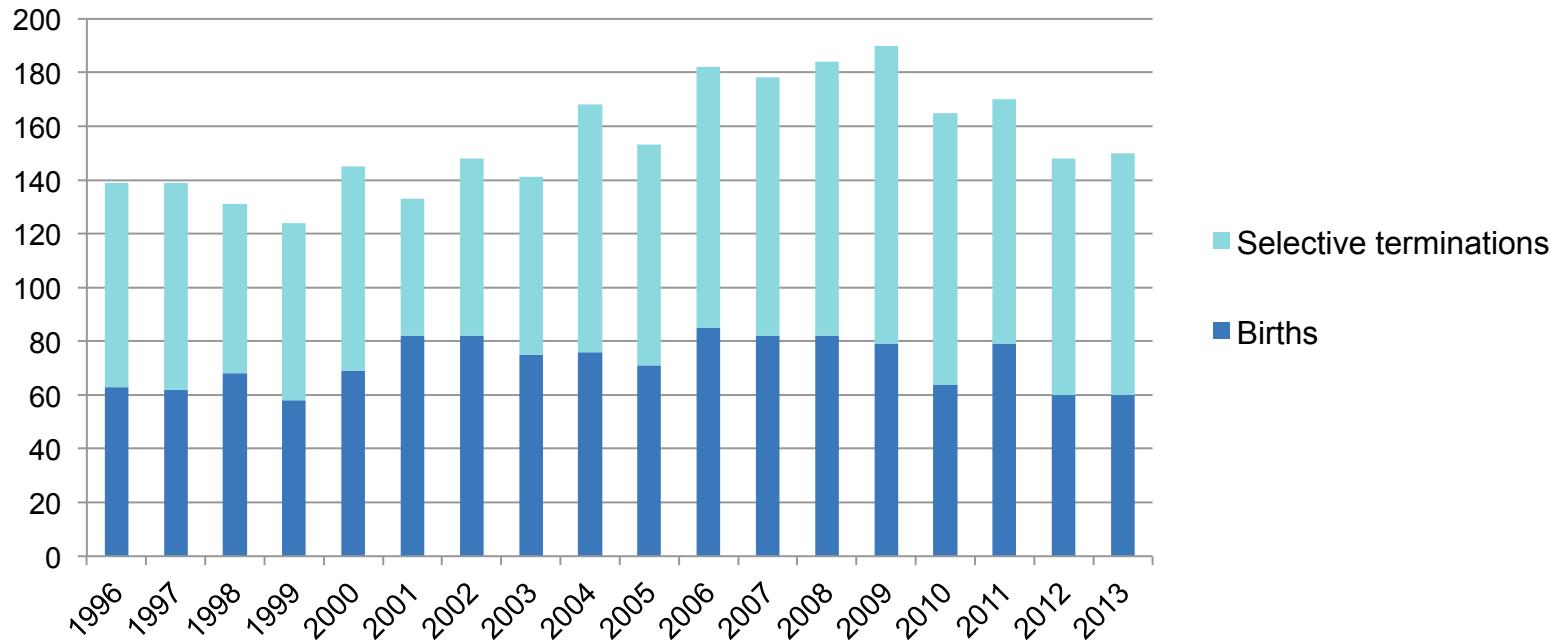
Cleft lip with or
without cleft palate



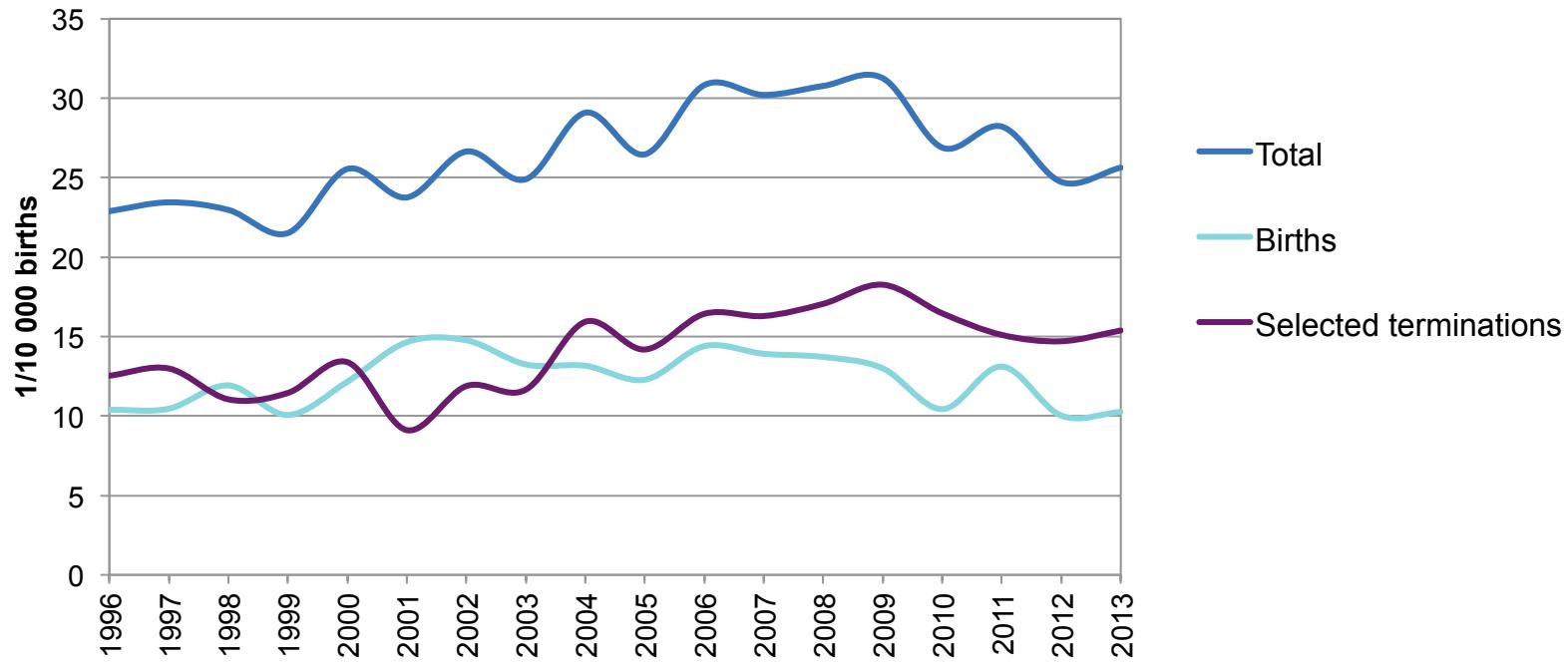
Prevalence of orofacial clefts



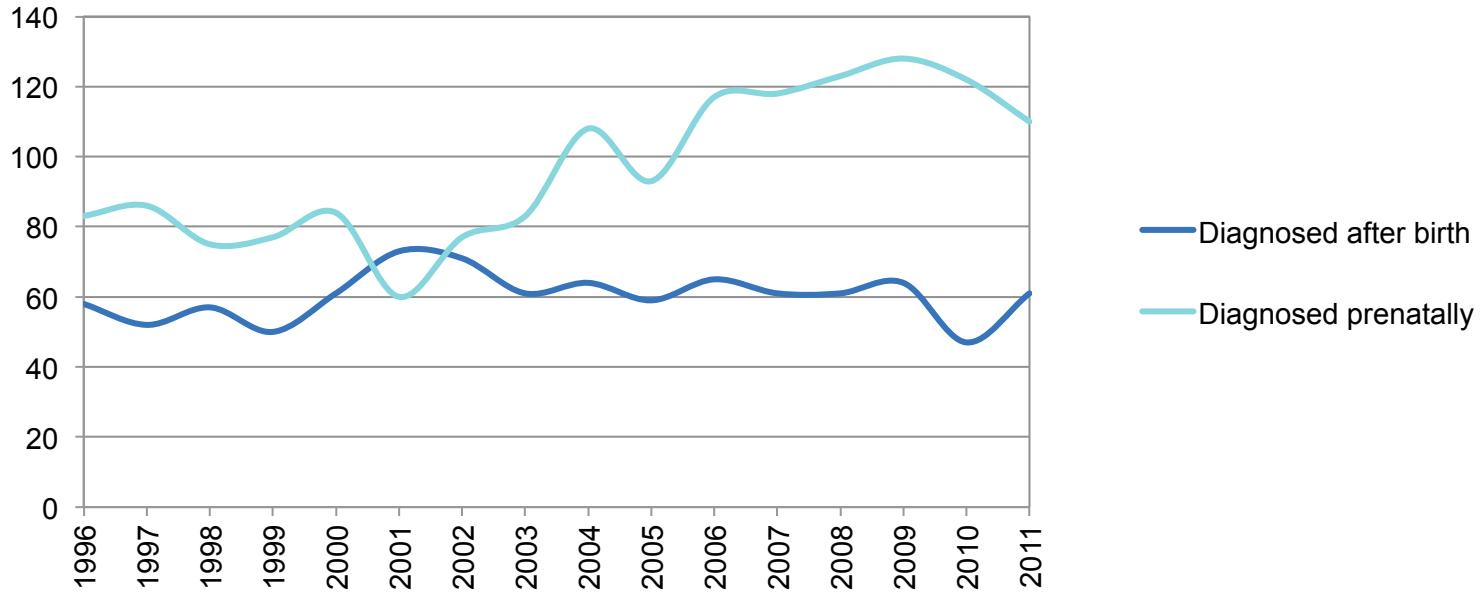
Trisomy 21 - Down syndrome Cases



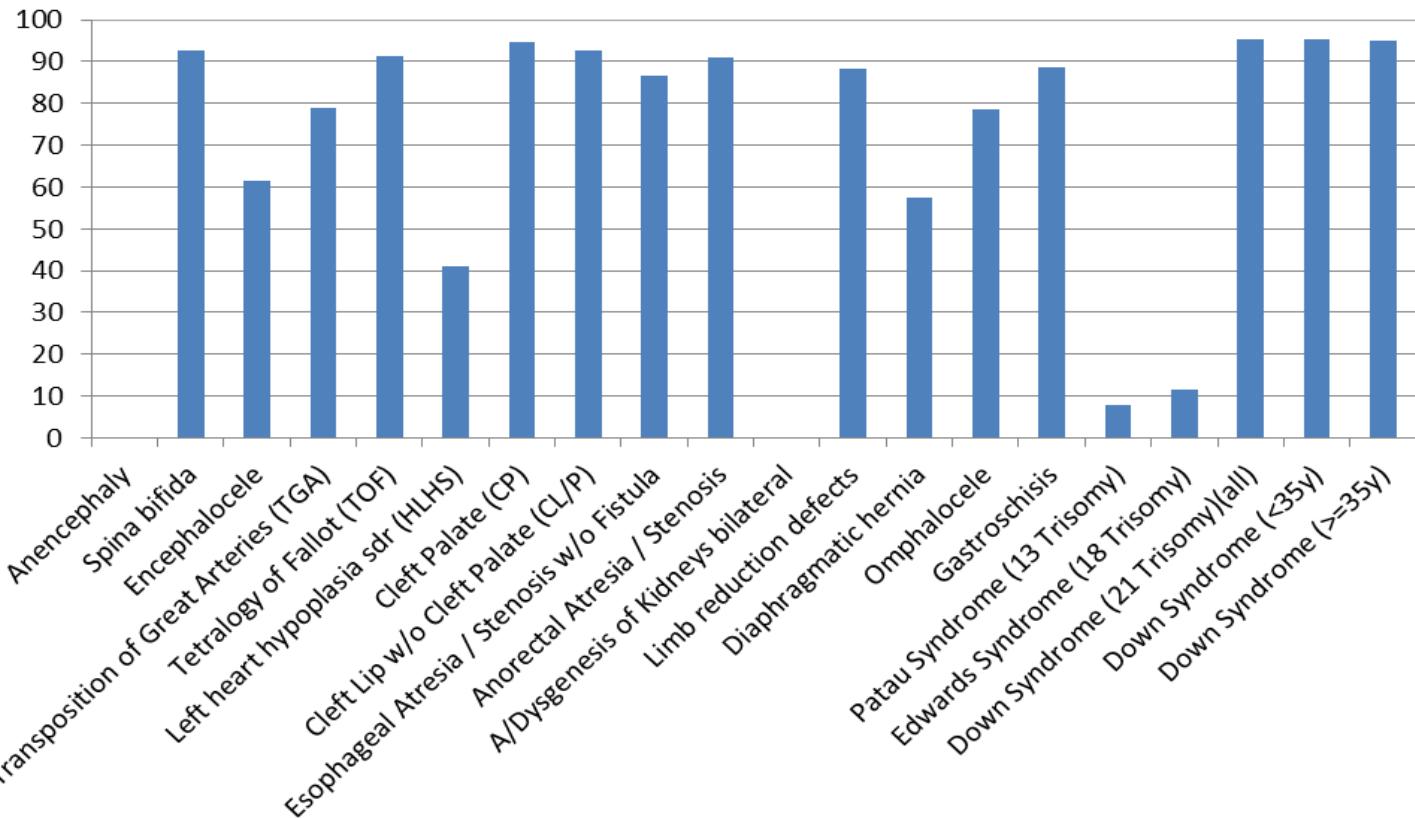
Trisomy 21 - Down syndrome Prevalence



Trisomy 21 - Down syndrome Cases



Alive at 1 year, % (1993-2011)



www.thl.fi/tilastot/epamuodostumat



**Epämuodostumarekisteri
THL
PL 30
00271 Helsinki**



NATIONAL INSTITUTE FOR HEALTH AND WELFARE

Engagements:

- MD, PhD, specialist in clinical genetics
- Main occupation
 - Chief physician of Finnish Malformation Register
- Secondary occupation
 - Private practitioner

