National Registry of Congenital Anomalies of the Czech Republic - 45 year experience

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http://www.vrozene-vady.cz/

Czech Republic - Geography

Regions and districts:
13 regions and the capital Prague (with regional status).
76 districts in total

Area: **78,866 km^2**

Czech Republic - Demography

Population: **10 467 542** (in 2008)

Population density: **132/km^2**

Annual births: approx. **120 000** (119 570 in 2008)

Capitol and largest city: **Prague** (1 200 000 inhabitants)

Life expectancy (years): **Males - 73.54**; **Females - 80.28**

Language: **Czech**

Ethnicity:

Czech 90.4 %, Moravian 3.7 %, Slovak 1.9 %, other 4 %

Religions:

Roman Catholic 27 %, Protestant 2 %, **unaffiliated 59 %**

Literacy rate: ≈ **100 %**

National Registry - History

National Registry of Congenital Anomalies of the Czech Republic (NRCA)

- Unofficial monitoring in former Czechoslovakia started in **1961**
- Official monitoring started on 1st of January **1964**
- **First stage (1964 – 1974)** – only **36** selected diagnoses of congenital anomalies (CA) were registered
- **Second stage (1975 – 1993) – 60** diagnoses of CA registered
- **Present time: (1994 – now) – all cases** in terminations of pregnancies (TOPs), stillbirths and live births are registered (age limit for reporting = **15 years**)

NRCA- Basic information

Registry: population based (whole area of the Czech Republic)

Law: The registration is compulsory, required by the Internal Law of Ministry of Health (nr. 14/2001). The database is run by the Institute of Health Information and Statistics of the Czech Republic

Cases: all cases in TOPs, live births and stillbirths (above 1000g) are reported, information about spontaneous abortions are poor

Coding: ICD-10 (international), no verbal description

Sources: Multiple sources, including departments of medical genetics, genetic laboratories, pediatric and neonatology departments, delivery units, ultrasound diagnostics departments etc. Reporting on the standardized paper form.

Termination of Pregnancy: Legal, up to the 24th week of gestation (from genetic reasons)

NRCA- Methodic

In children with congenital anomaly we collect:

demographic information: birthplace + birth date

personal information - birth weight, birth length, gestational age at birth, congenital anomalies (up to eight ICD-10 diagnoses), eventually date and cause of death

About the mother we collect following information:

number of gravidity and parity, plurality of pregnancy, age, occupation, education level, diseases and medication in pregnancy (ATC groups)

NRCA – Prenatal Diagnosis

- Unofficial monitoring of the prenatal diagnosis started in **1975** (prenatal diagnosis of Down Syndrome)
- Official monitoring started in **1994**
- **We are collecting following information:**
  diagnosis, gestation week at diagnosis, used method of prenatal diagnosis and eventually **the information about termination of pregnancy**

NRCA – Strengths and Weaknesses

+ Population based registry covers the whole area of republic

+ Registration is compulsory and financed by the Government

+ We are using ICD-10 coding (up the eight codes for one case)

+ It is possible to link data from NRCA to data from another National Registries (Registry of Mothers, Registry of Newborns…)

+ Quite a lot of information about both mother and newborn

+/- We have information about drug exposure in pregnancy but only in cases of congenital anomalies– not in controls

- No possibility to collect additional information about cases (only the information according to valid law – 14/2001)

- Currently – no financial support for new projects and analyzes

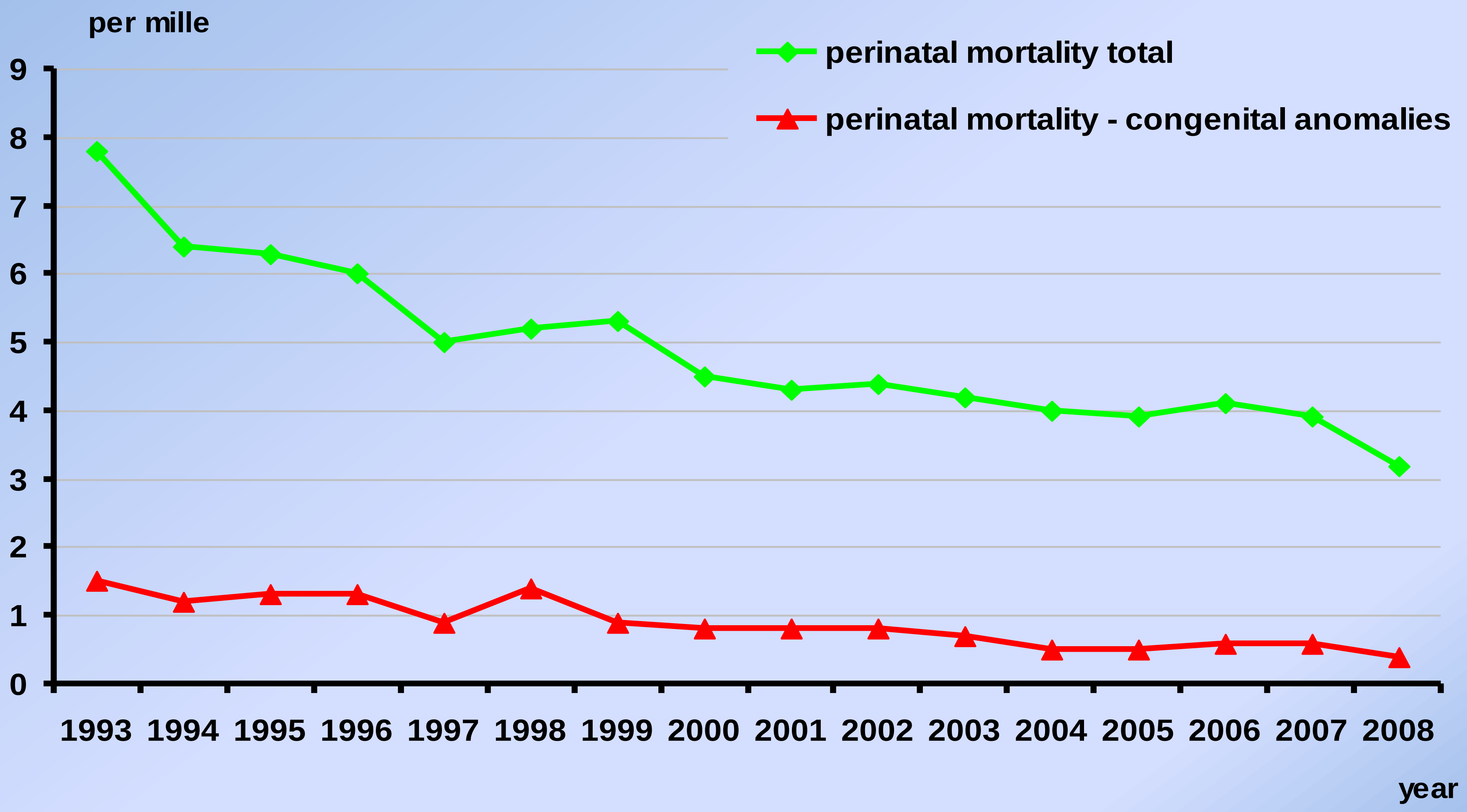
NRCA – International Cooperation I

- The NRCA was the founding member of ICBDMS (ICBDSR) in **1974** and is a full member today.
- **ICBDSR (International Clearinghouse for Birth Defects Surveillance and Research)** is a voluntary non profit International Organization affiliated with WHO. The Organization brings together birth defect surveillance and research programmes from around the world with the aim of investigating and preventing birth defects and lessening the impact of their consequences. (http://www.icbdsr.org/).
- The centre of the Clearinghouse is in **Rome (Italy)** – the current director is **prof. Pierpaolo Mastroiacovo.**

NRCA – International Cooperation II

- The NRCA became an affiliate member of EUROCAT in **2009** and is going to become associate member next years.
- **EUROCAT (European Surveillance of Congenital Anomalies)** is an European network of population-based registries for the epidemiologic surveillance of congenital anomalies. Its duties are to provide essential epidemiologic information on congenital anomalies in Europe, to evaluate the effectiveness of primary prevention and many more. (http://www.eurocat.ulster.ac.uk/).
- The centre of the organization is at the University of Ulster **(United Kingdom)** – the current project leader is **prof. Helen Dolk.**

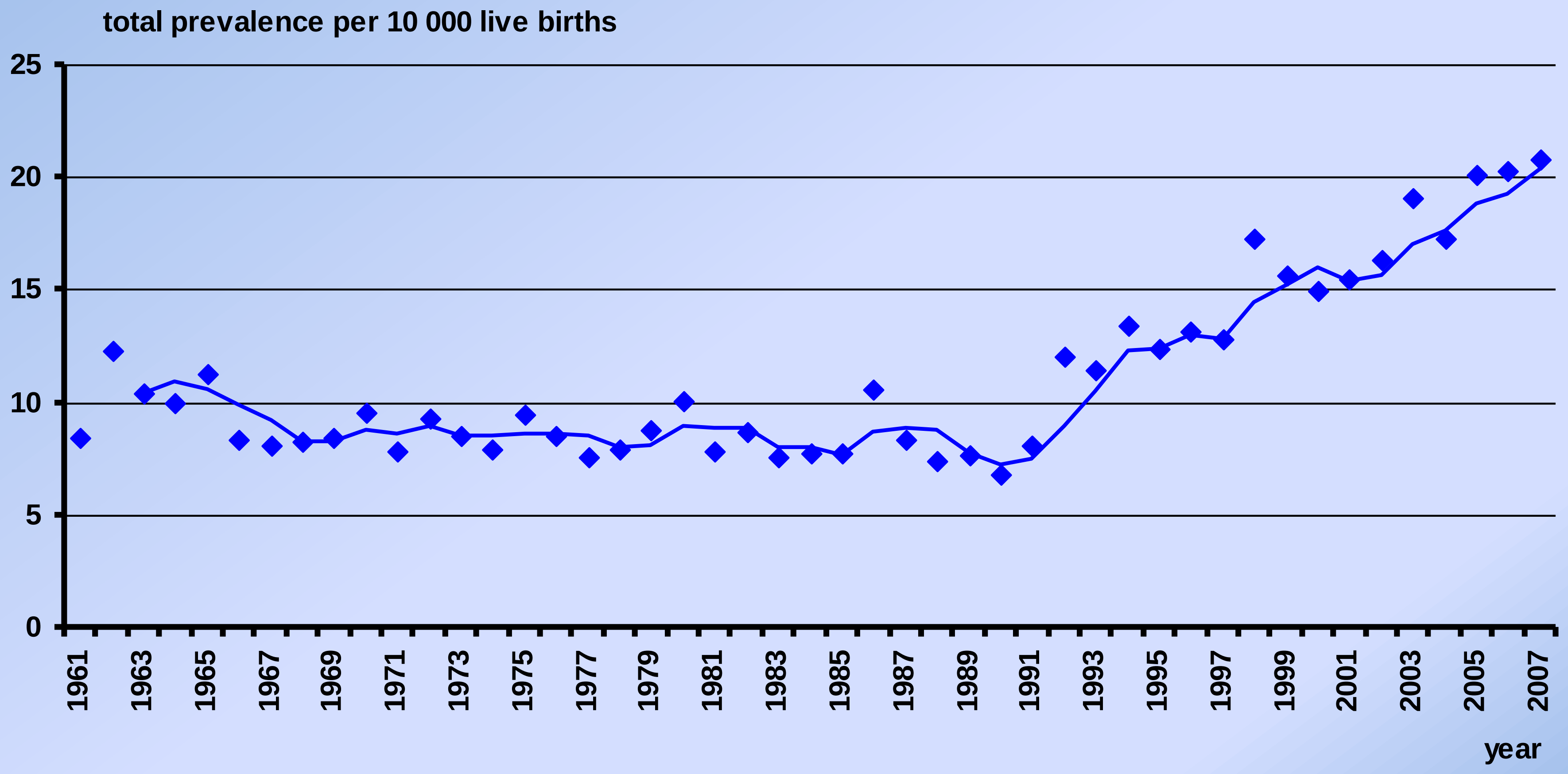
Perinatal Mortality in the Czech Republic



Down Syndrome in the Czech Republic

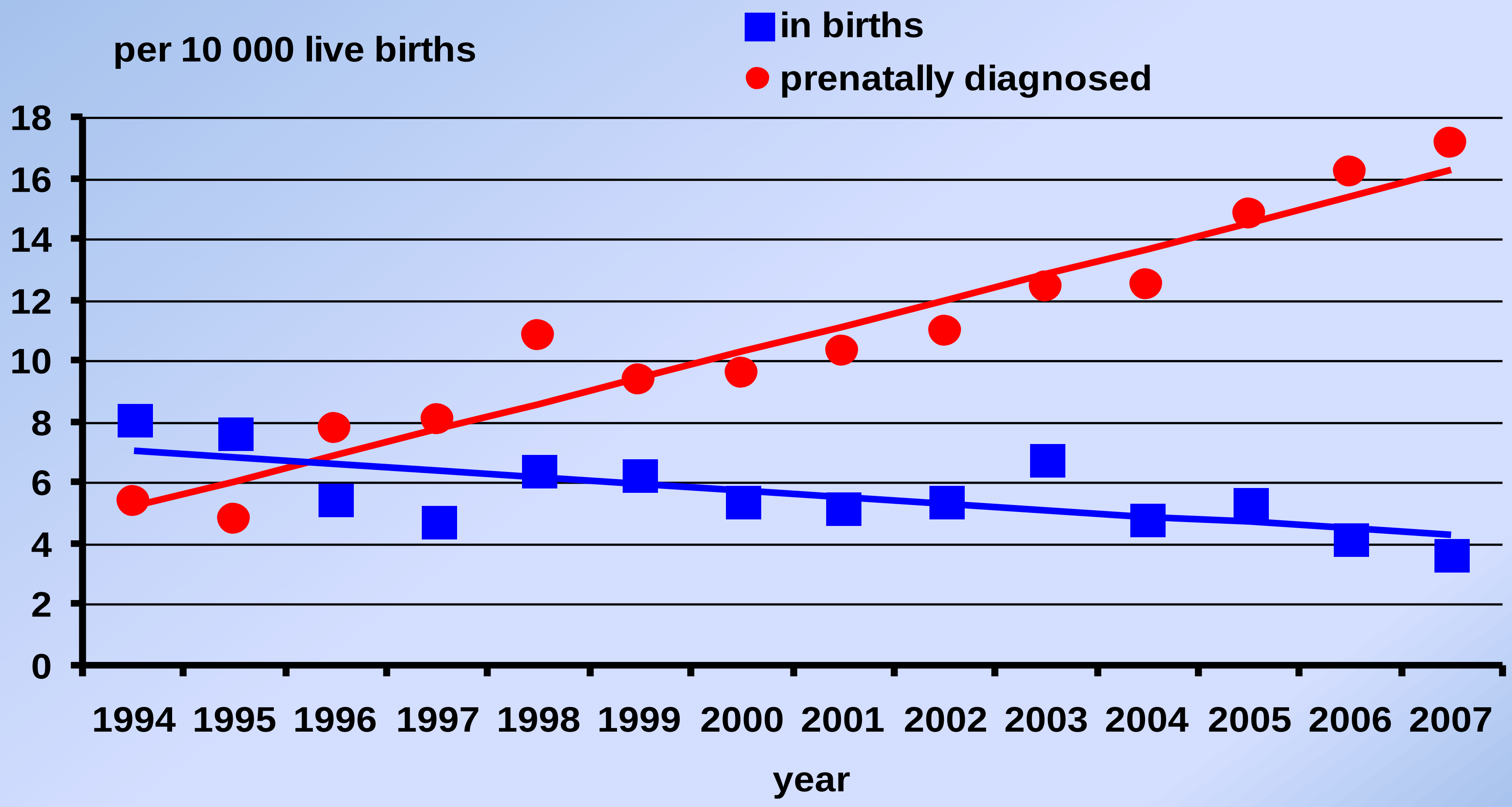
Total prevalence per 10 000 live births, 1961 – 2007

(including prenatally diagnosed cases)



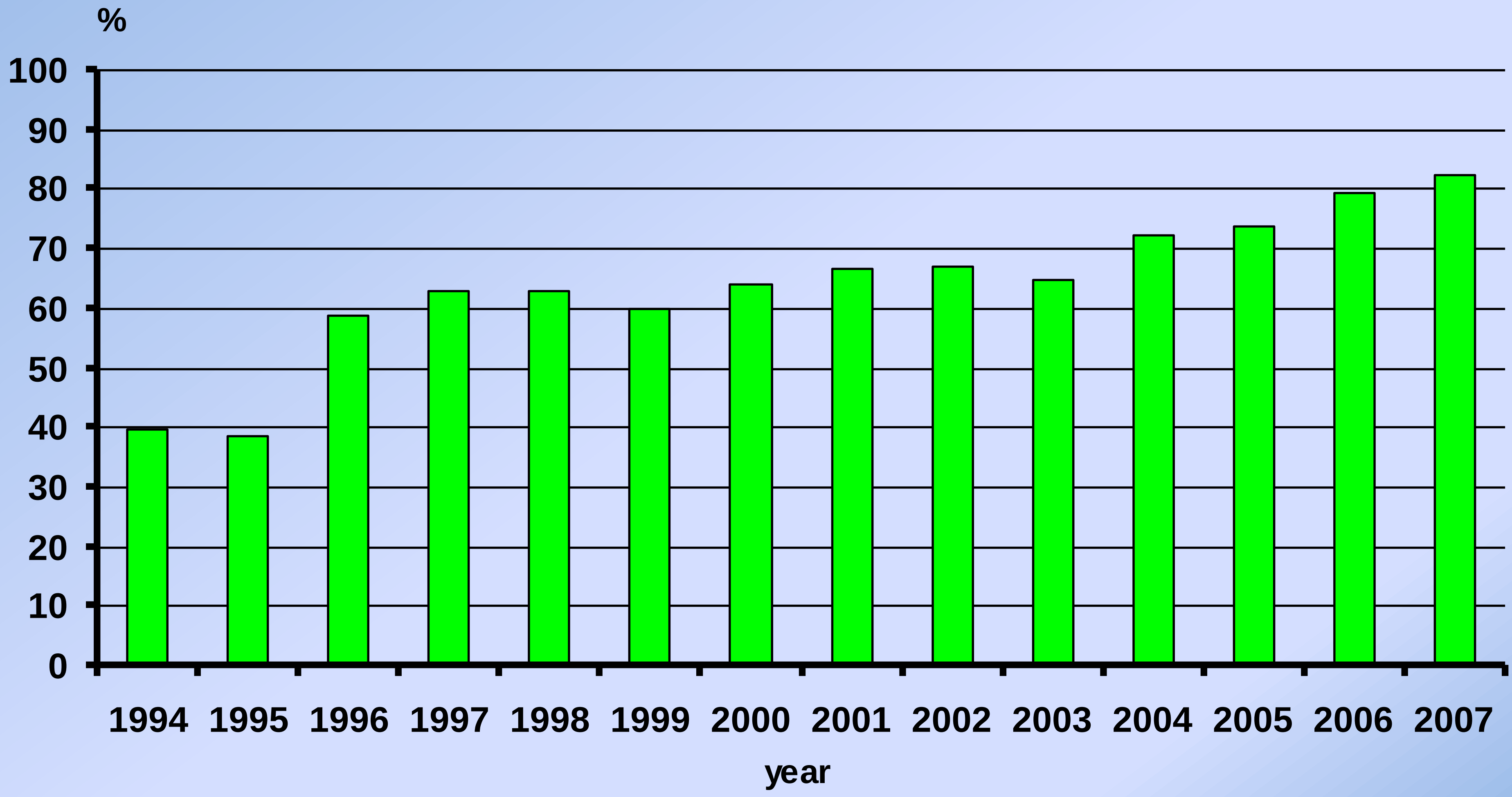
Down Syndrome in the Czech Republic

Prevalence in births and in prenatally diagnosed cases per 10 000 live births, 1994 - 2007



Down Syndrome in the Czech Republic

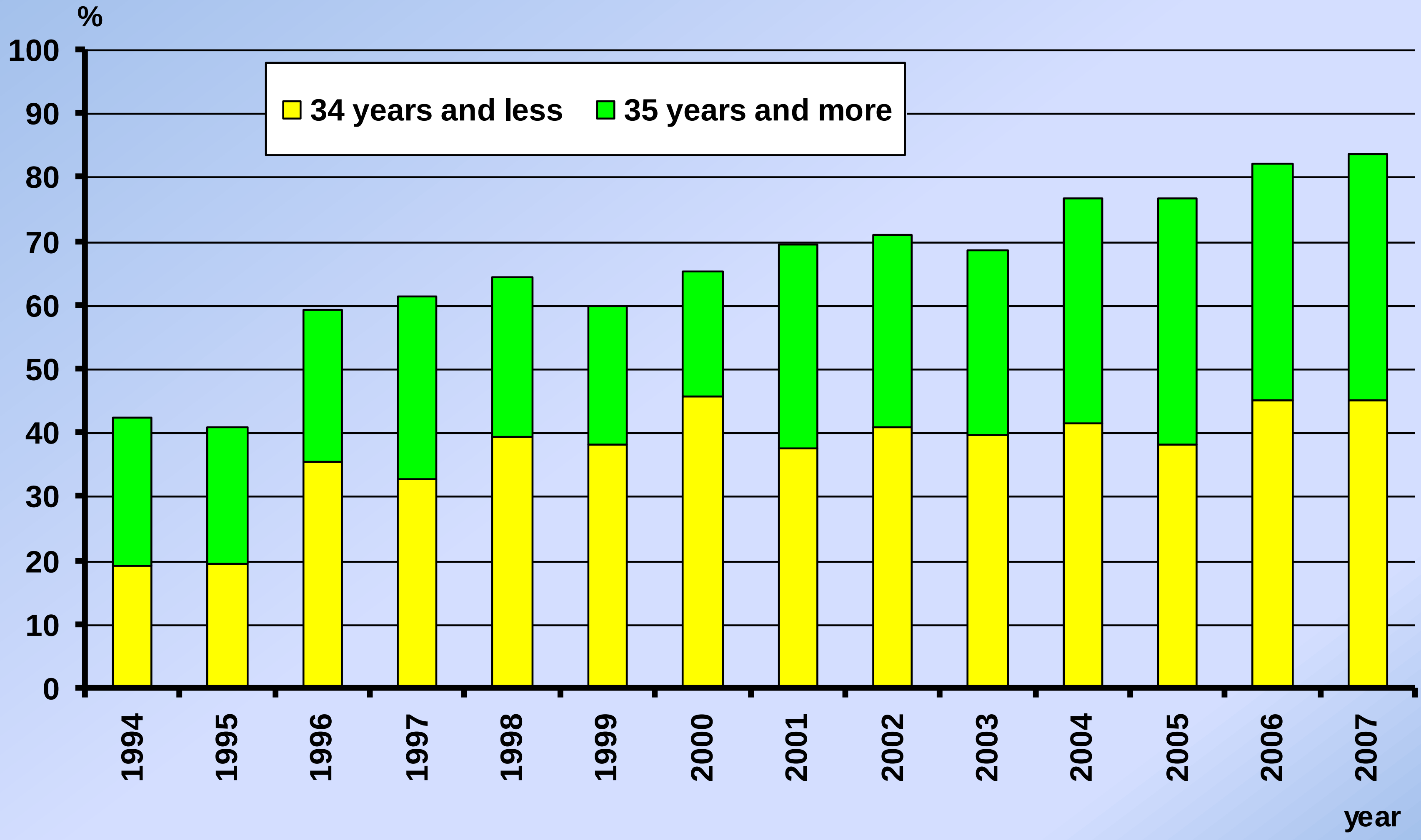
Proportion of terminations among DS cases, 1994 – 2007



Down Syndrome in the Czech Republic

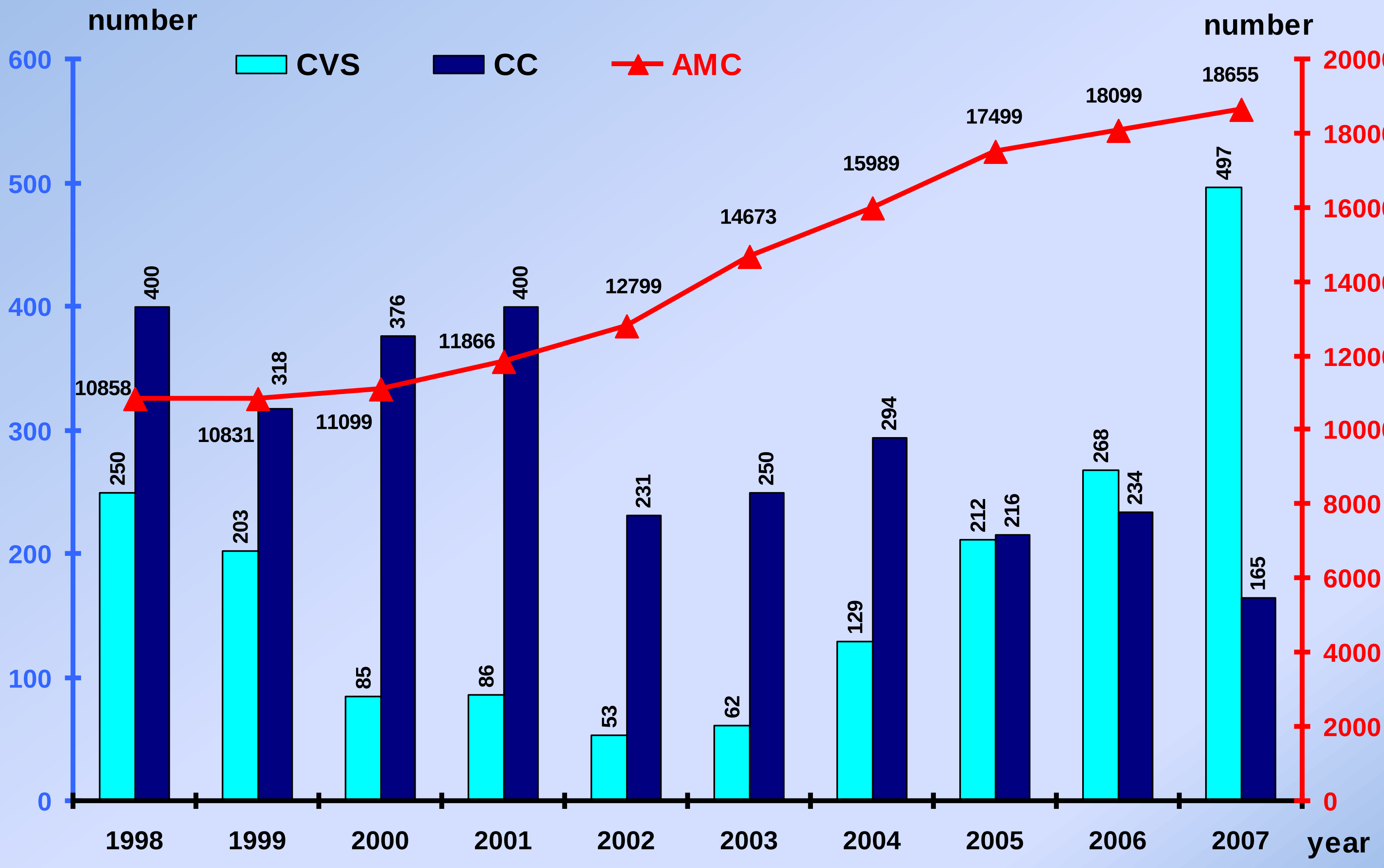
Efficiency of prenatal diagnosis, 1994 – 2007

(according to the maternal age; Frequency of prenatally diagnosed cases)

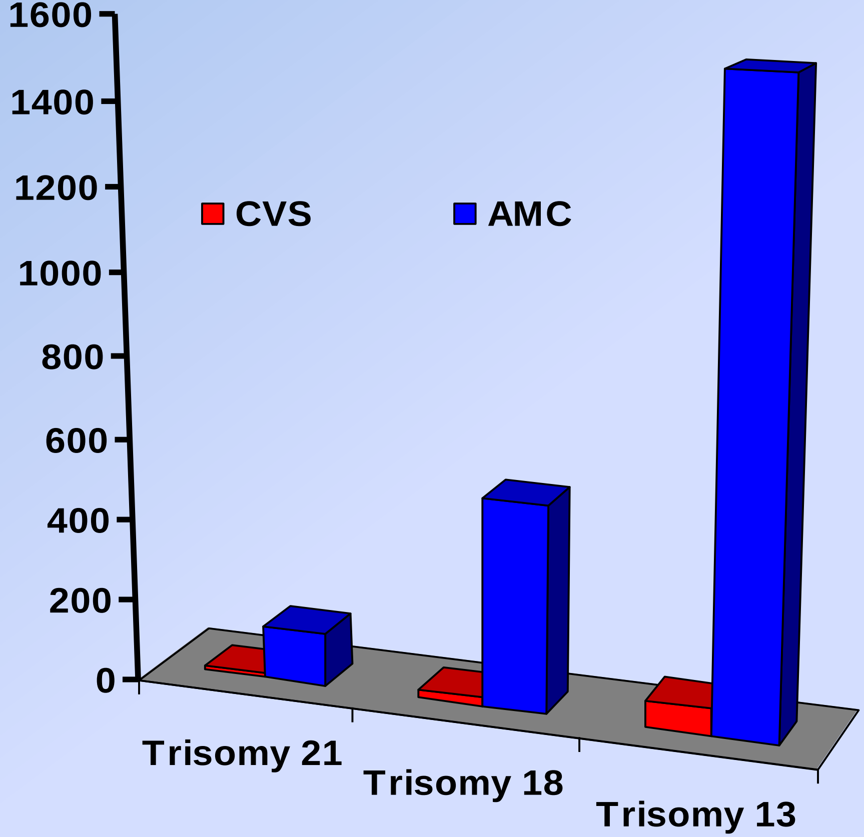


Methods of invasive prenatal diagnosis

Absolute numbers, 1998 - 2007



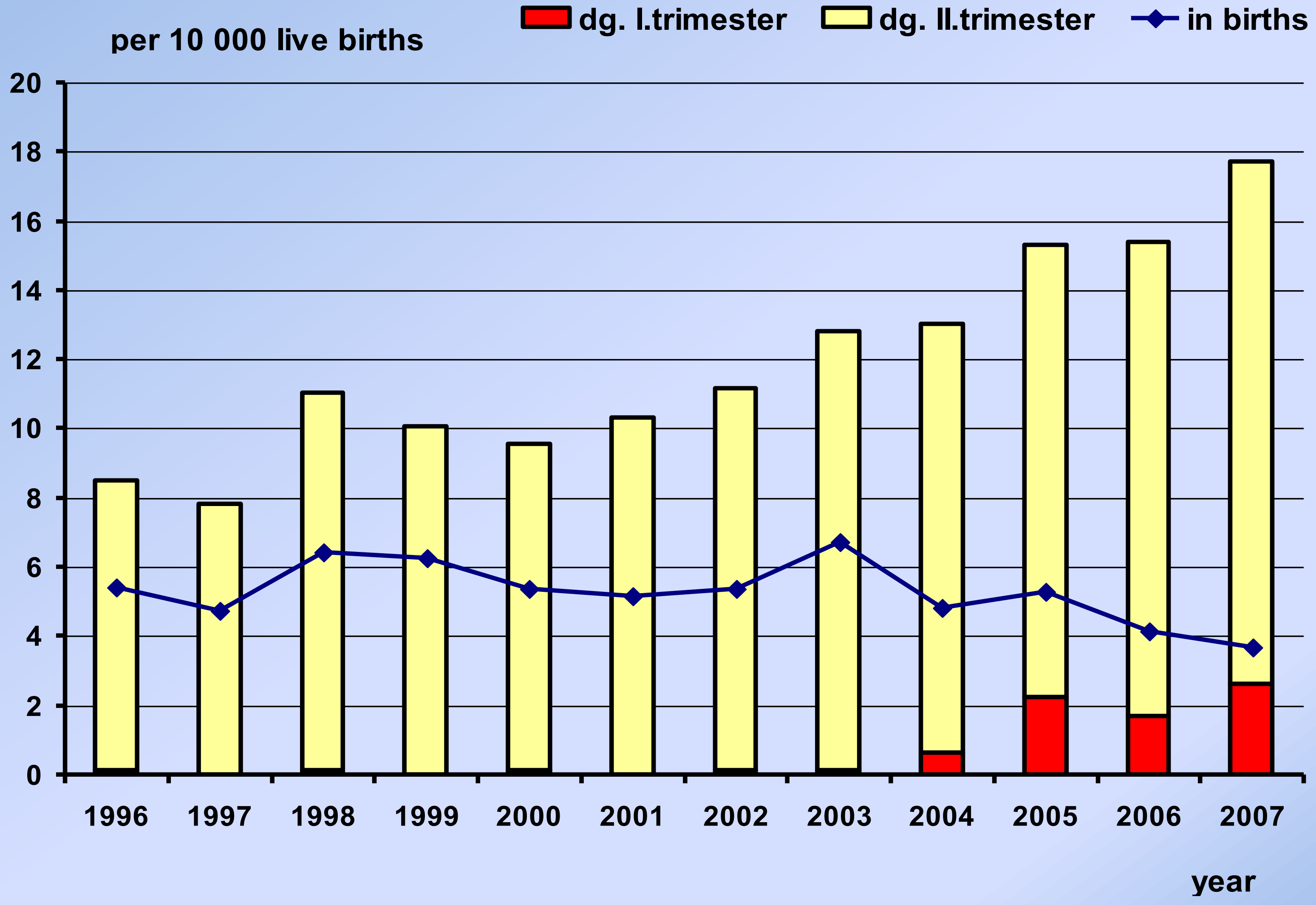
Number of procedures of invasive prenatal diagnosis needed for identification of one case of autosomal trisomy.



	Trisomy 21	Trisomy 18	Trisomy 13
🟥 CVS	10,92	20,05	65,89
🟦 AMC	129,65	508,41	1530,71

Down Syndrome in the Czech Republic

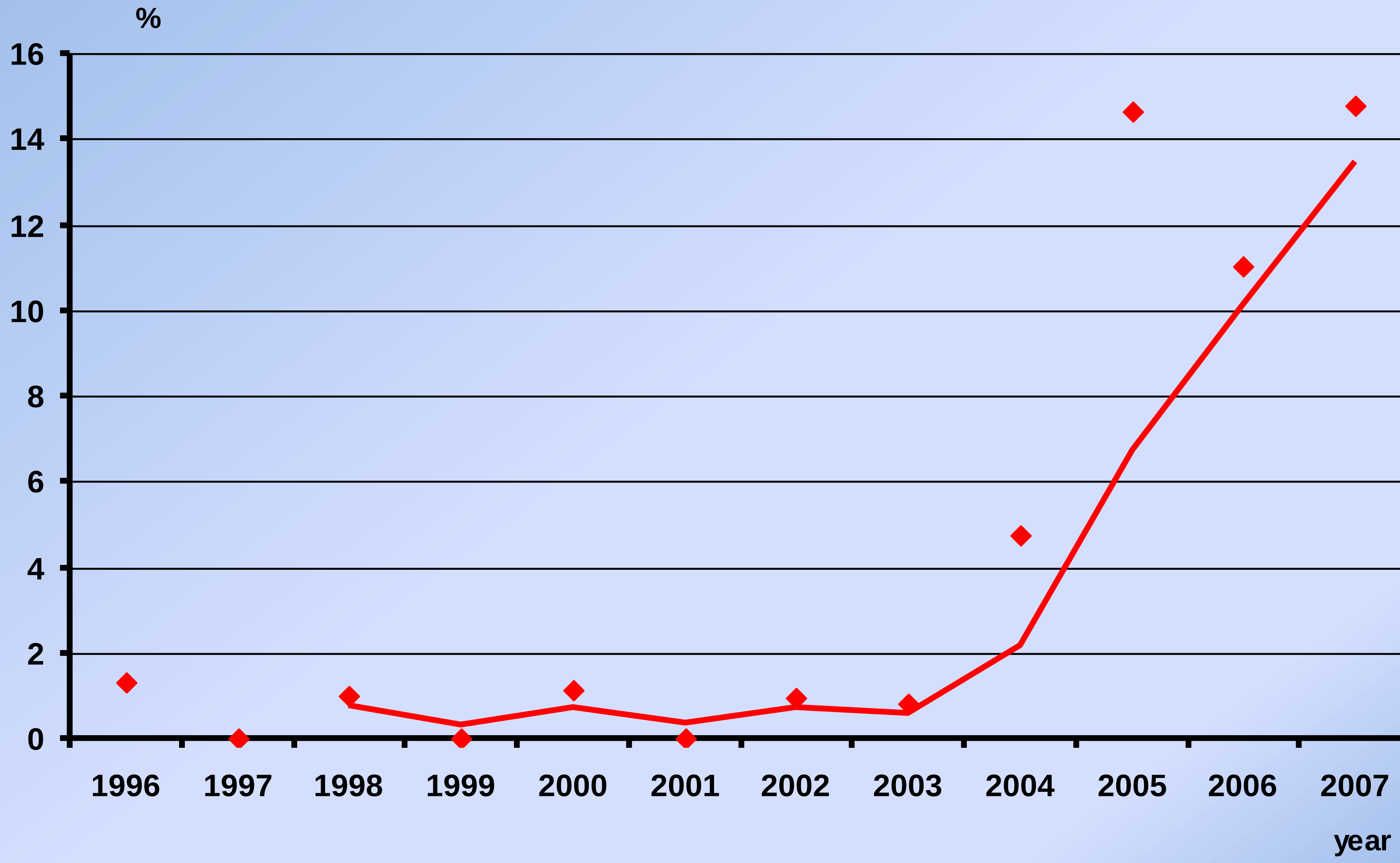
Relative number of prenatally (I. trimester or II. trimester) and postnatally diagnosed cases, 1996 – 2007



Down Syndrome in the Czech Republic

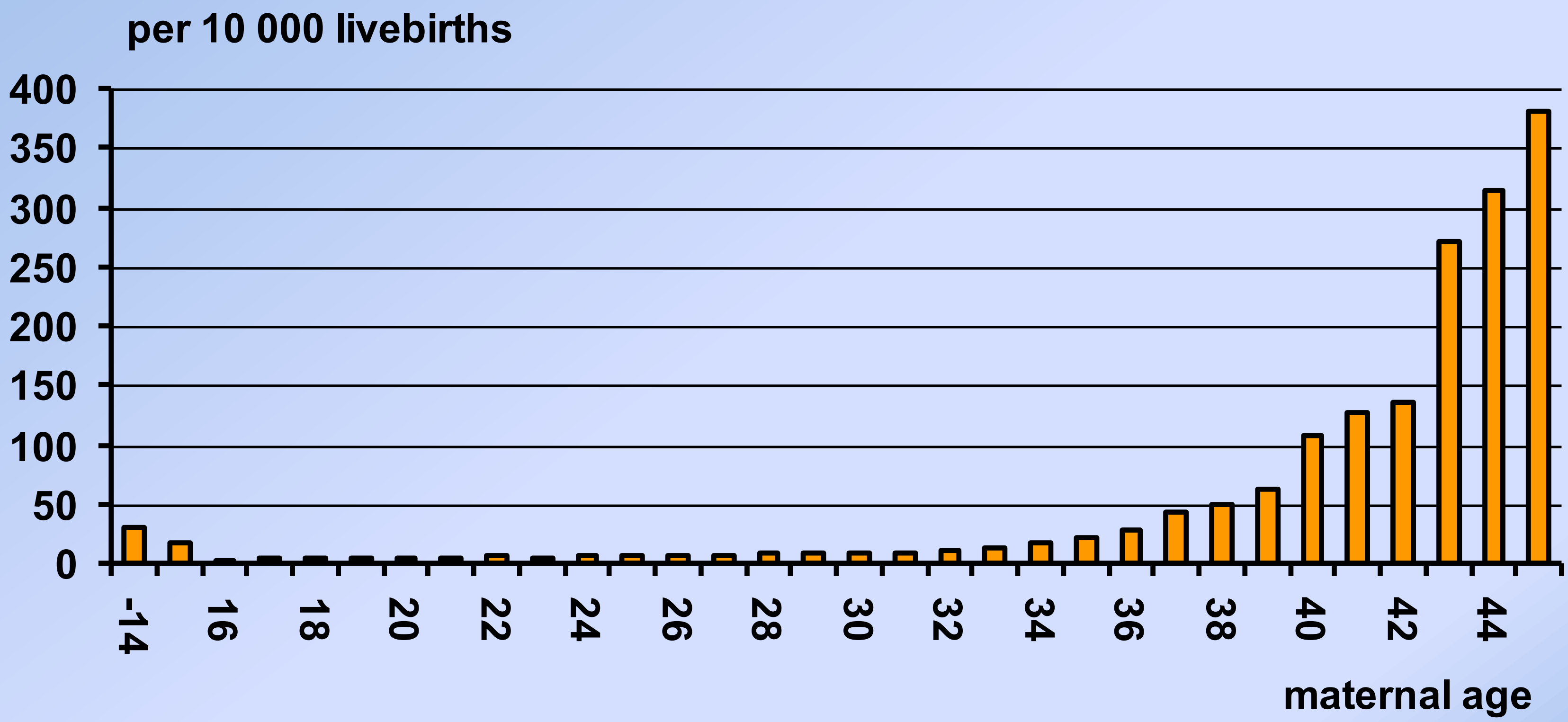
Prenatal diagnosis, 1996 – 2007

Frequency of cases identified during the first trimester



Down Syndrome in the Czech Republic

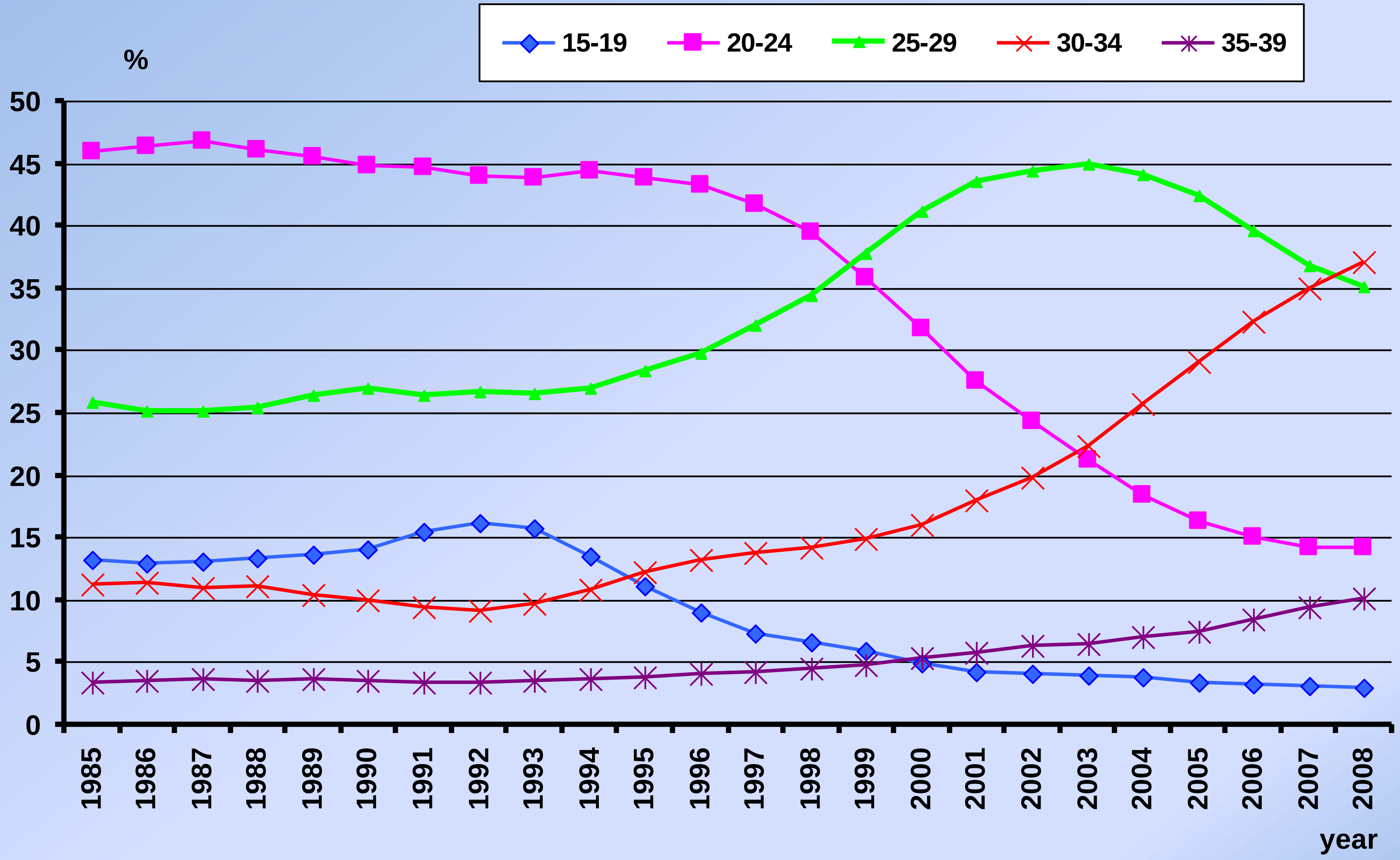
Prevalance of Down Syndrome – Depending on the maternal age



-14 = 14 years and less…

Maternal age in the Czech Republic

Trends in the age-subgroups, all delivering mothers, 1985 – 2008



Acknowledgement

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NRCA – Contact information

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