

NATIONAL REGISTRY OF CONGENITAL ANOMALIES OF THE CZECH REPUBLIC: 50 YEARS OF SURVEILLANCE HISTORY AND CHALLENGES OF THE FUTURE

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<http://www.vrozenevady.cz/>

1964 50 years anniversary 2014

National Registry of Congenital Anomalies of the Czech Republic

Selected congenital anomalies surveillance programs in the world - Timeline

- 1962 – Hungary 
- 1963 – Finland 
- 1964 – Czechoslovakia 
- 1966 – Canada (British Columbia since r. 1952), Israel  
- 1967 – Georgia (USA), Norway, South Africa   
- 1968 – Denmark 
- 1970 – Northern Ireland (Belfast area since 1957) 

Czech Republic - 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**)
- **Near future:** no age limit, additional diagnoses (rare diseases), electronic registration, OMIM and Orphanet codes etc.



Czech Republic - Present State

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. Additional data on prenatally diagnosed cases are collected thanks to the country-wide cooperation.

Cases: all cases in TOPs, live births and stillbirths are reported

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.

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



Czech Republic

Population: 10 548 527

Area: 78,866 km²

Regions: 13 regions and the capital Prague; 76 districts in total

Population density: 133/km²

Annual births: approx. 100 000

Capitol and largest city: Prague (1 241 000 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%



International Cooperation

ICBDSR

Established in 1974

World-Wide organization

CZE: Full membership
(1974)



<http://www.icbdsr.org>

EUROCAT

Established in 1979

European organization

CZE: Associate membership
(2009)



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

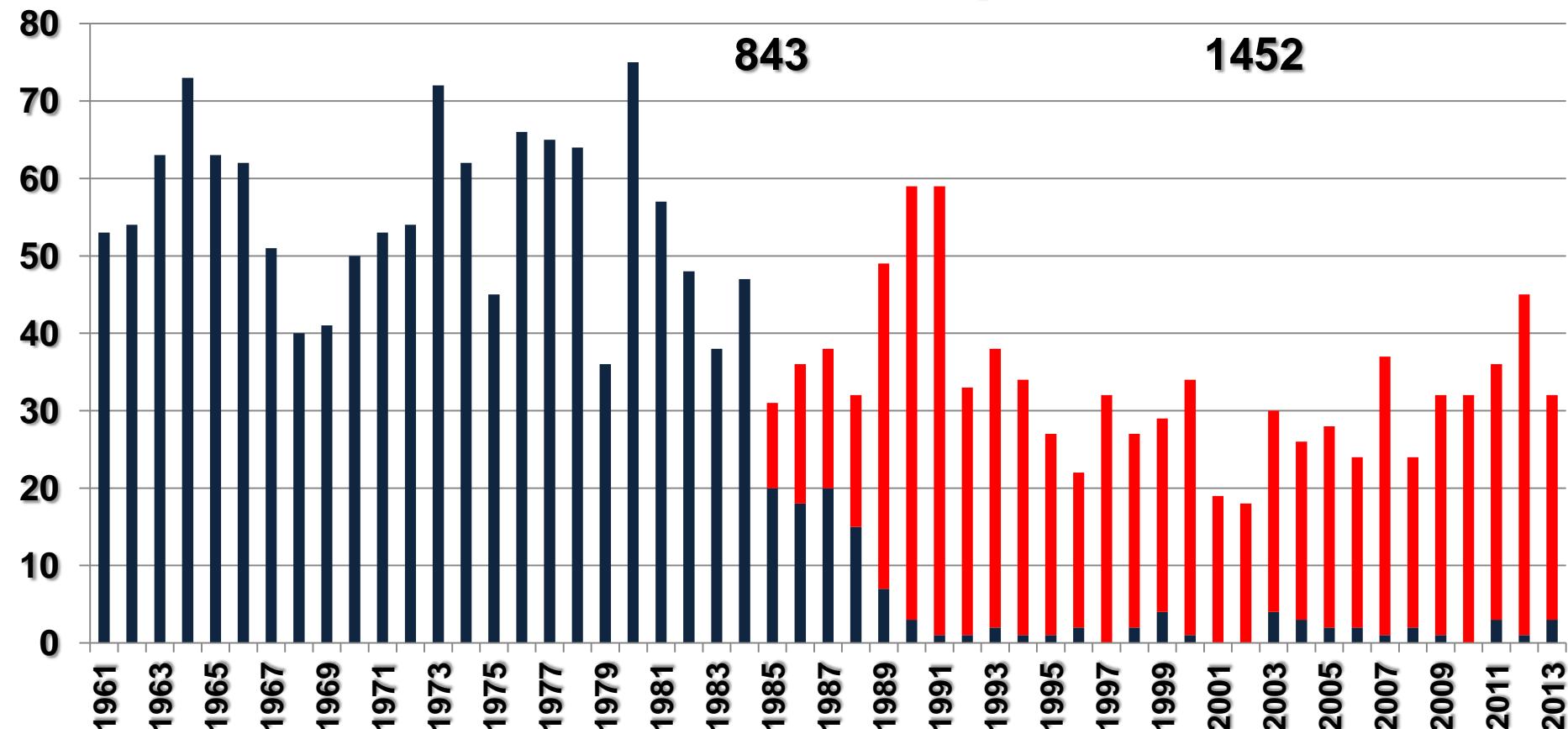
Anencephaly

50+ years

Absolute numbers

■ Prenatal diagnosis

■ Births



Anencephaly – All cases in live births and prenatal diagnosis

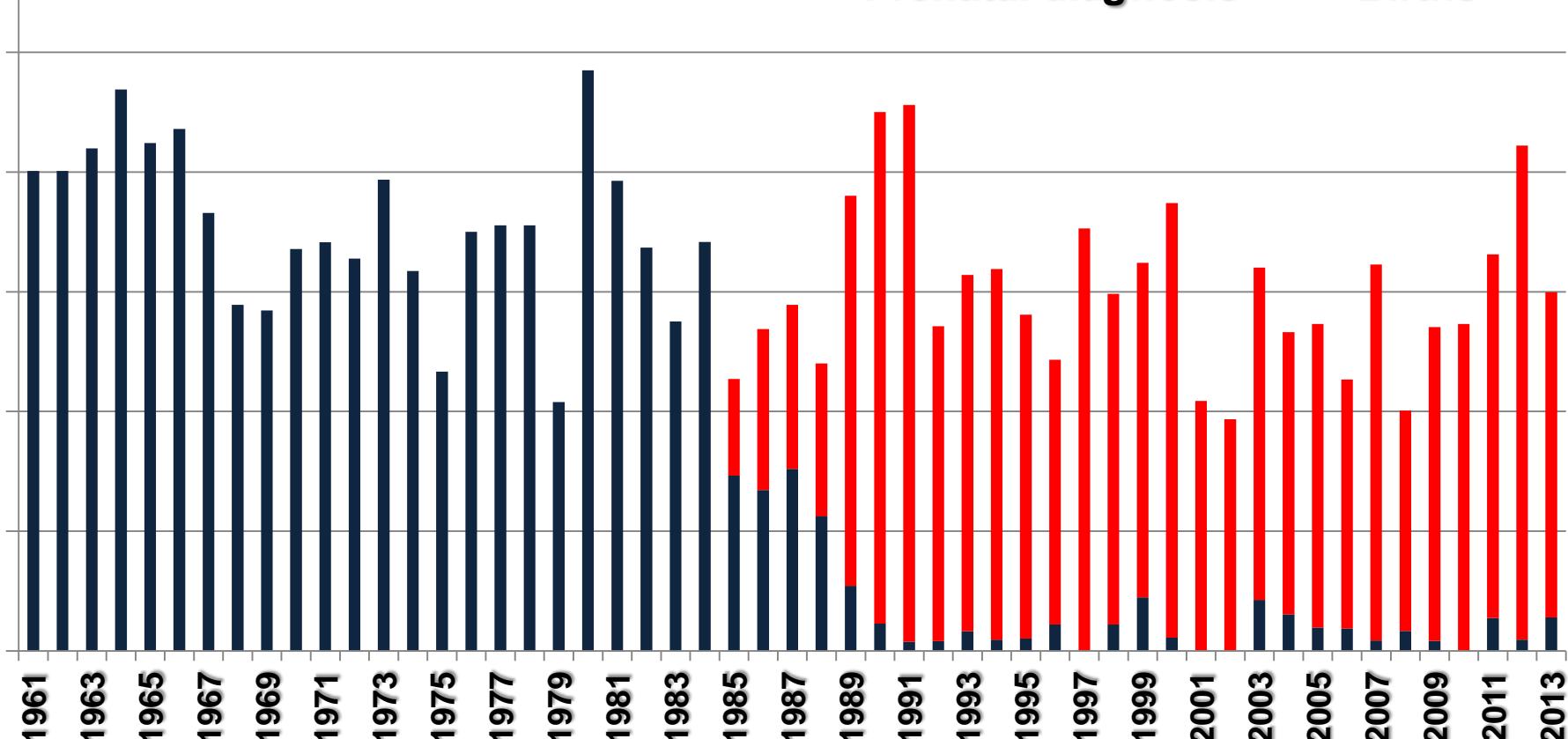
Anencephaly

50+ years

Per 10,000 live births

■ Prenatal diagnosis

■ Births



Anencephaly – All cases in live births and prenatal diagnosis

Down syndrome

50+ years

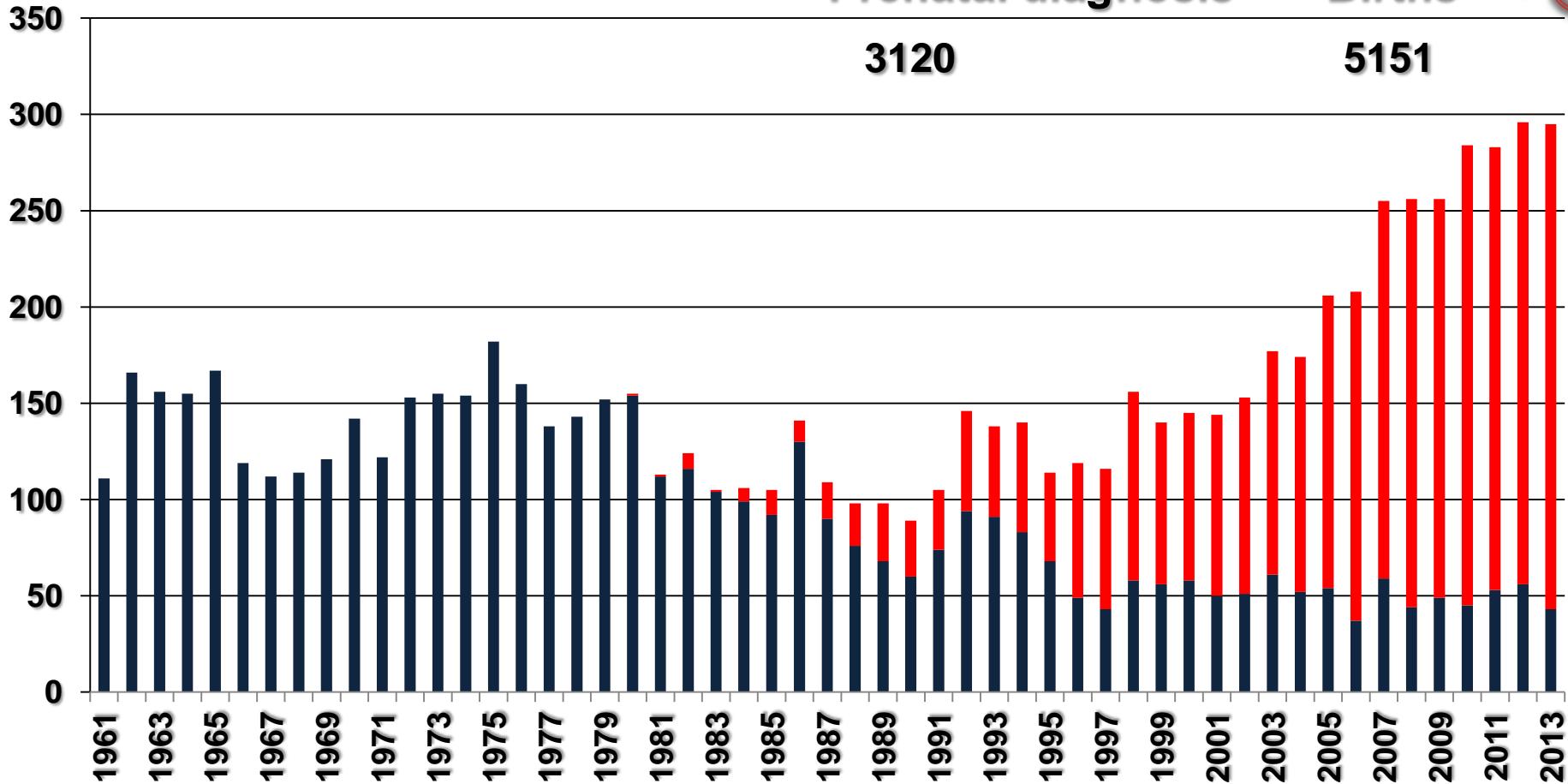
Absolute numbers

■ Prenatal diagnosis

■ Births

3120

5151



Down syndrome – All cases in live births and prenatal diagnosis

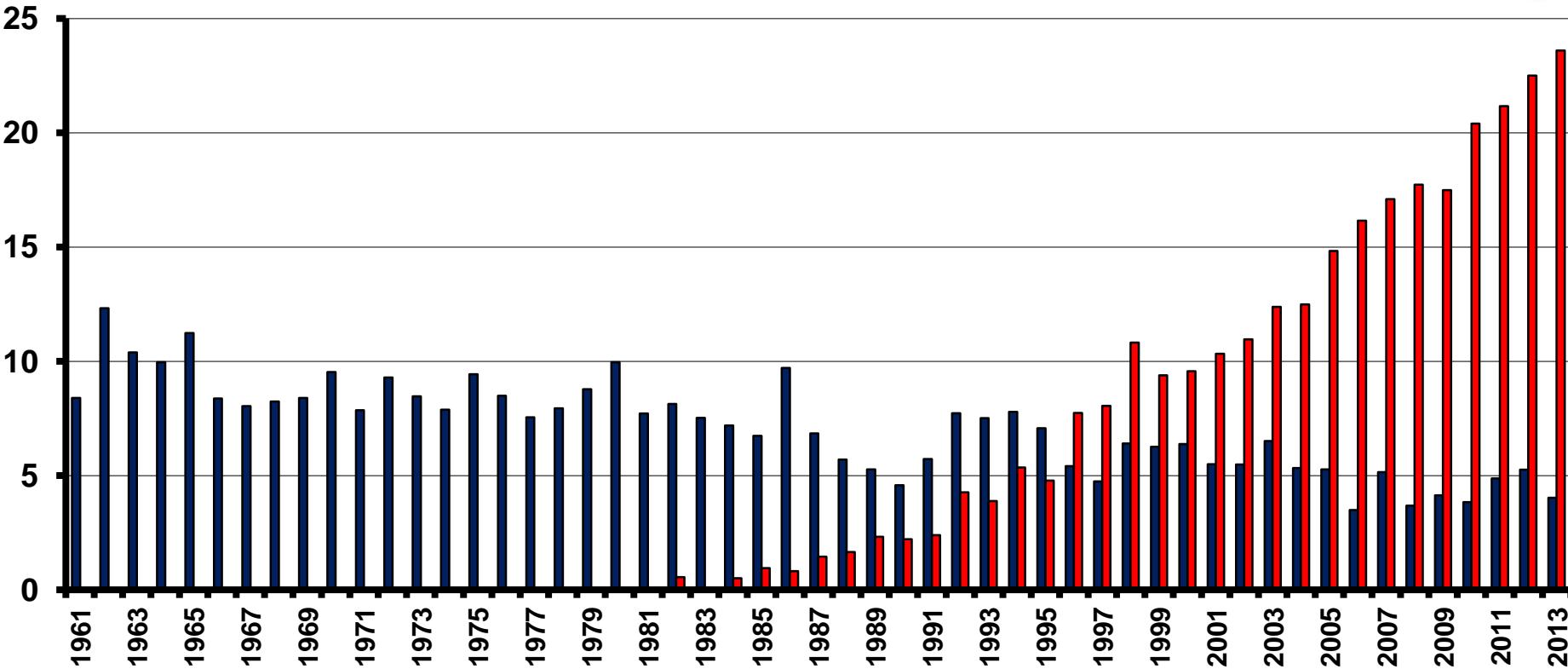
Down syndrome

50+ years

Per 10.000 of live births

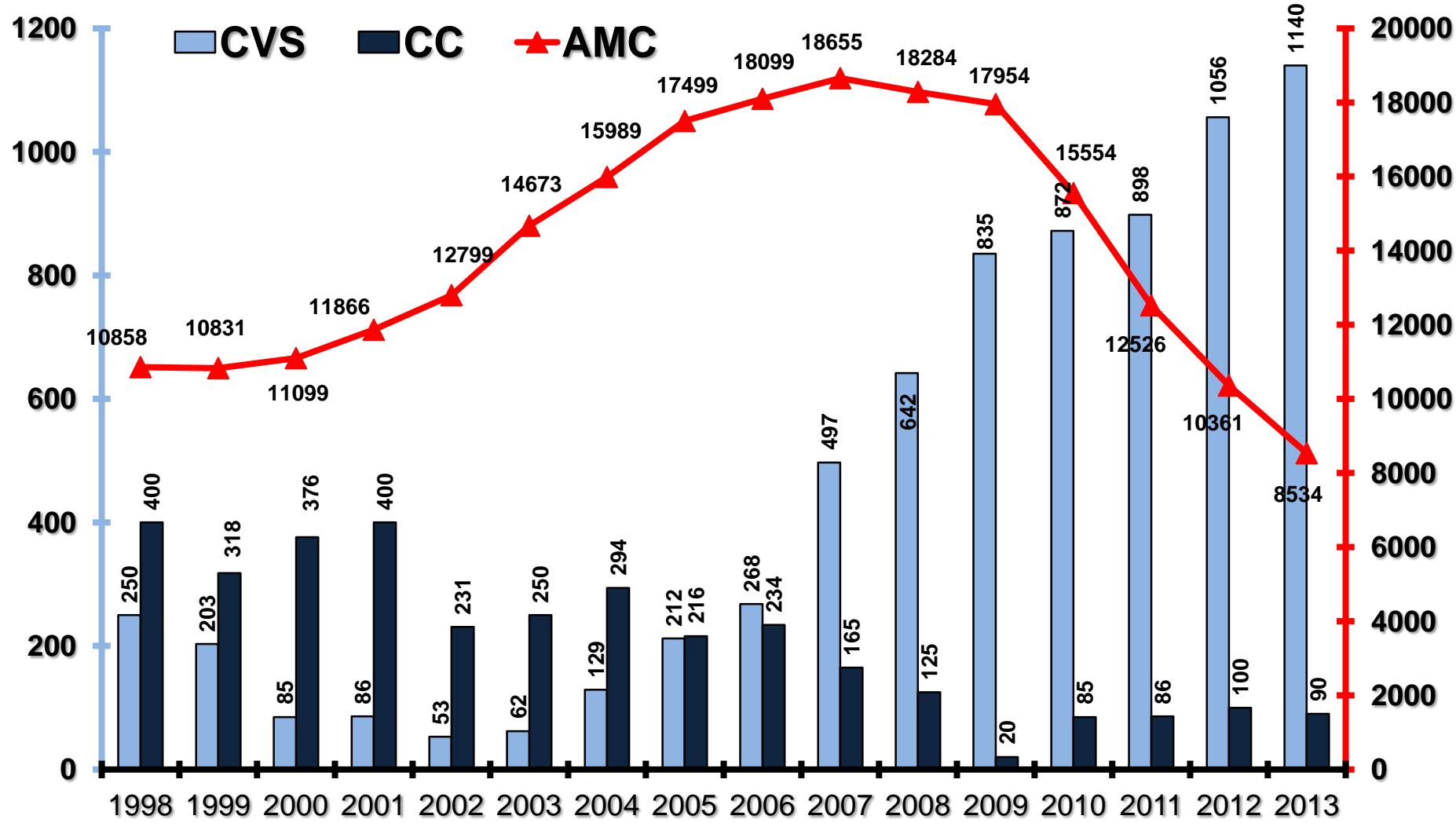
■ Births

■ Prenatal diagnosis

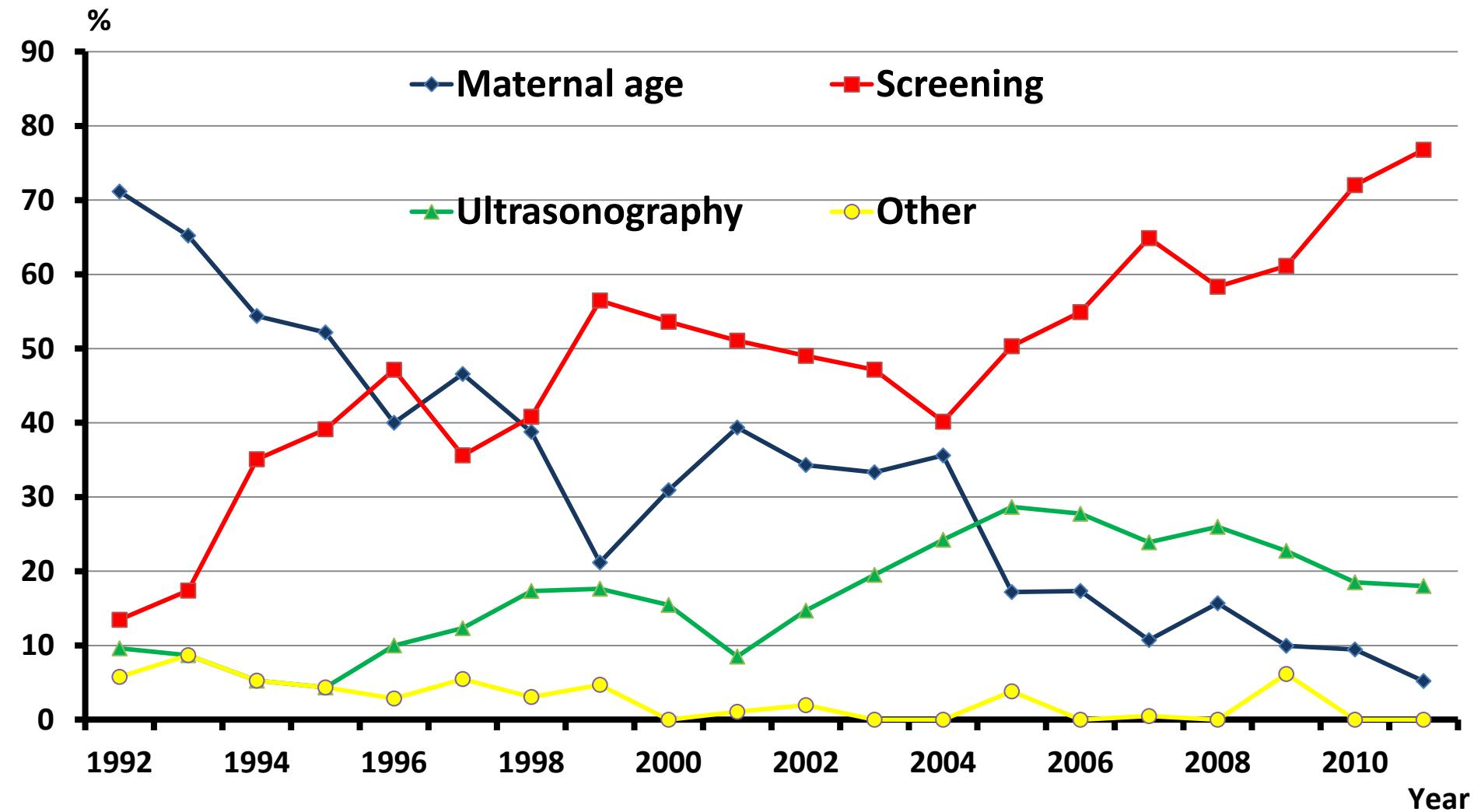


Down syndrome – All cases in live births and prenatal diagnosis

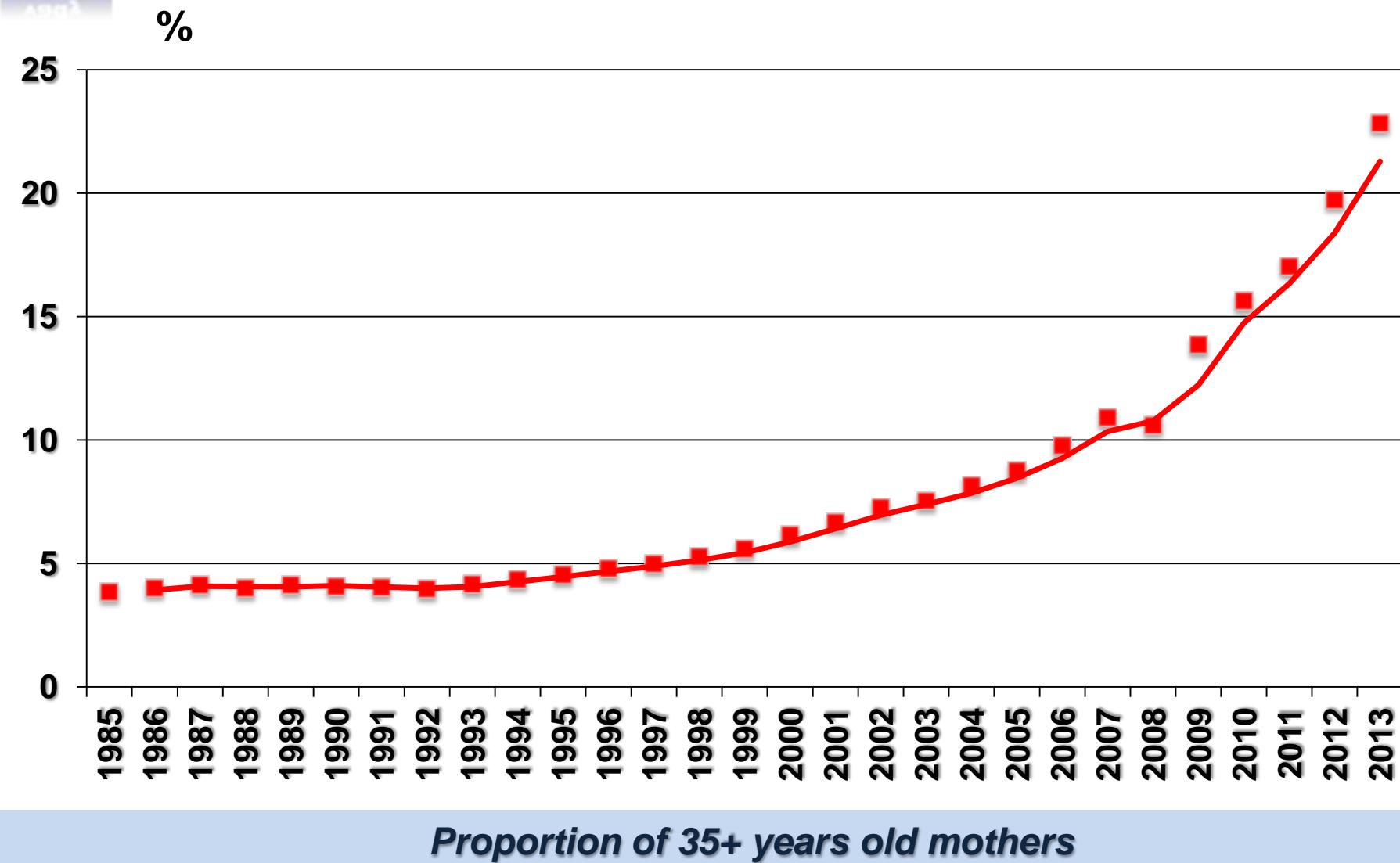
Invasive prenatal diagnosis



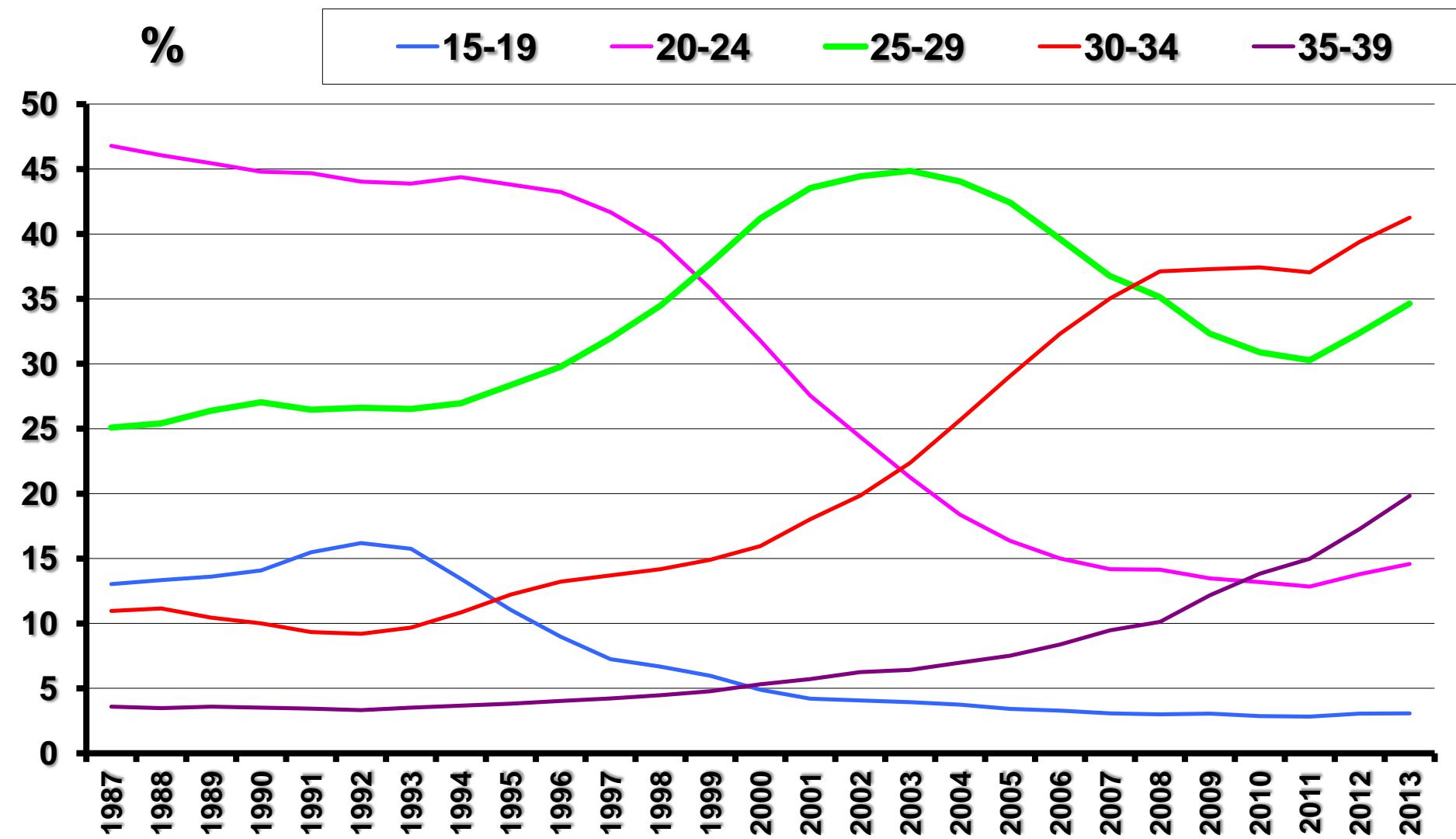
Prenatal diagnosis - Indications



Maternal age – Time trends



Maternal age – Time trends



Conclusions

1. *The number of prenatally diagnosed cases of Down syndrome is increasing*
2. *The number of Down syndrome cases in live births is decreasing*
3. *The indication criteria for the invasive prenatal diagnosis are changing during last years*
4. *The average maternal age is notably increasing during last years*
5. *The early prenatal diagnosis (during the first trimester of gravidity) is becoming much more important during last years*

Thank you for your attention!

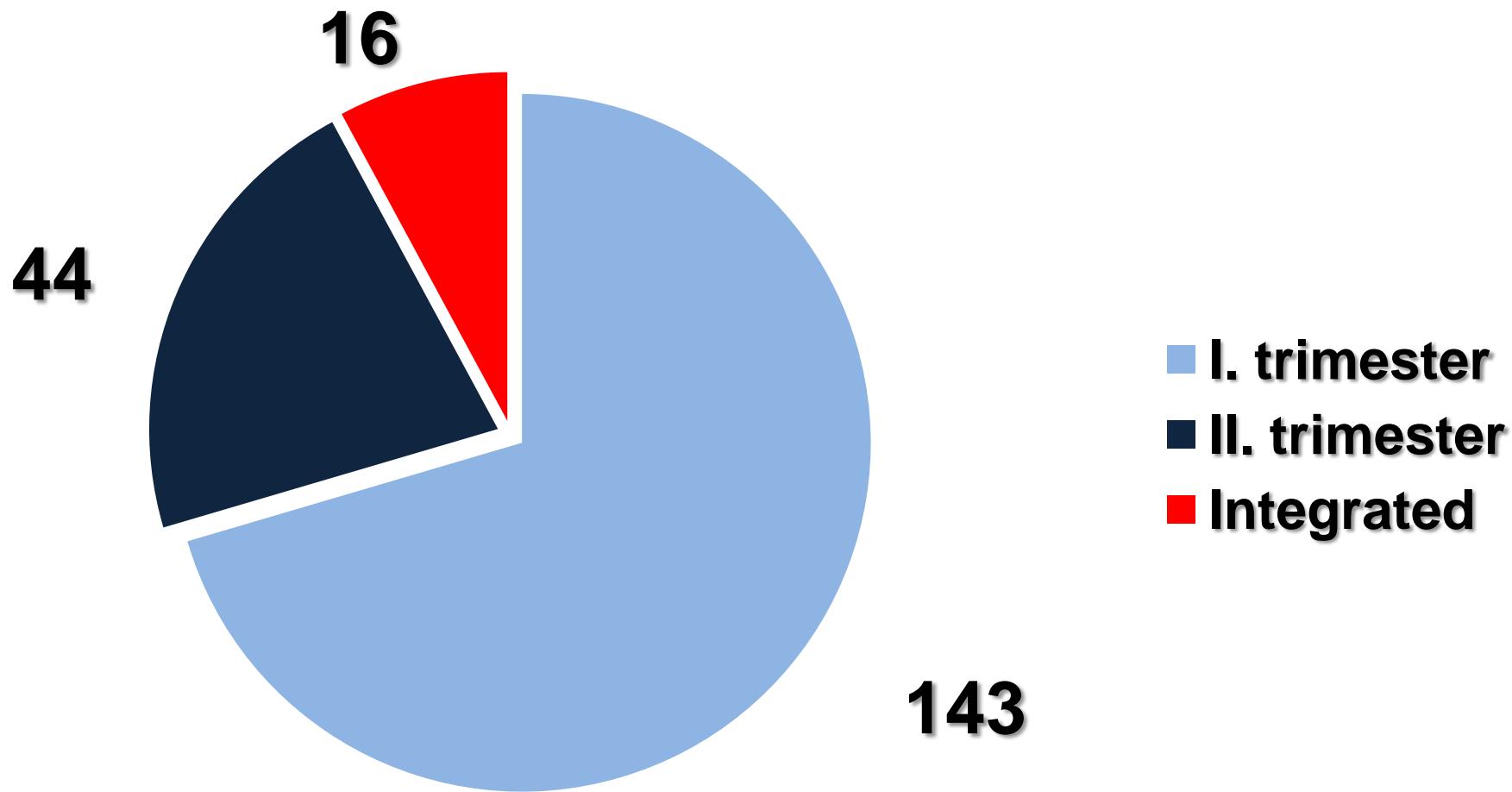


Vrozené
vady

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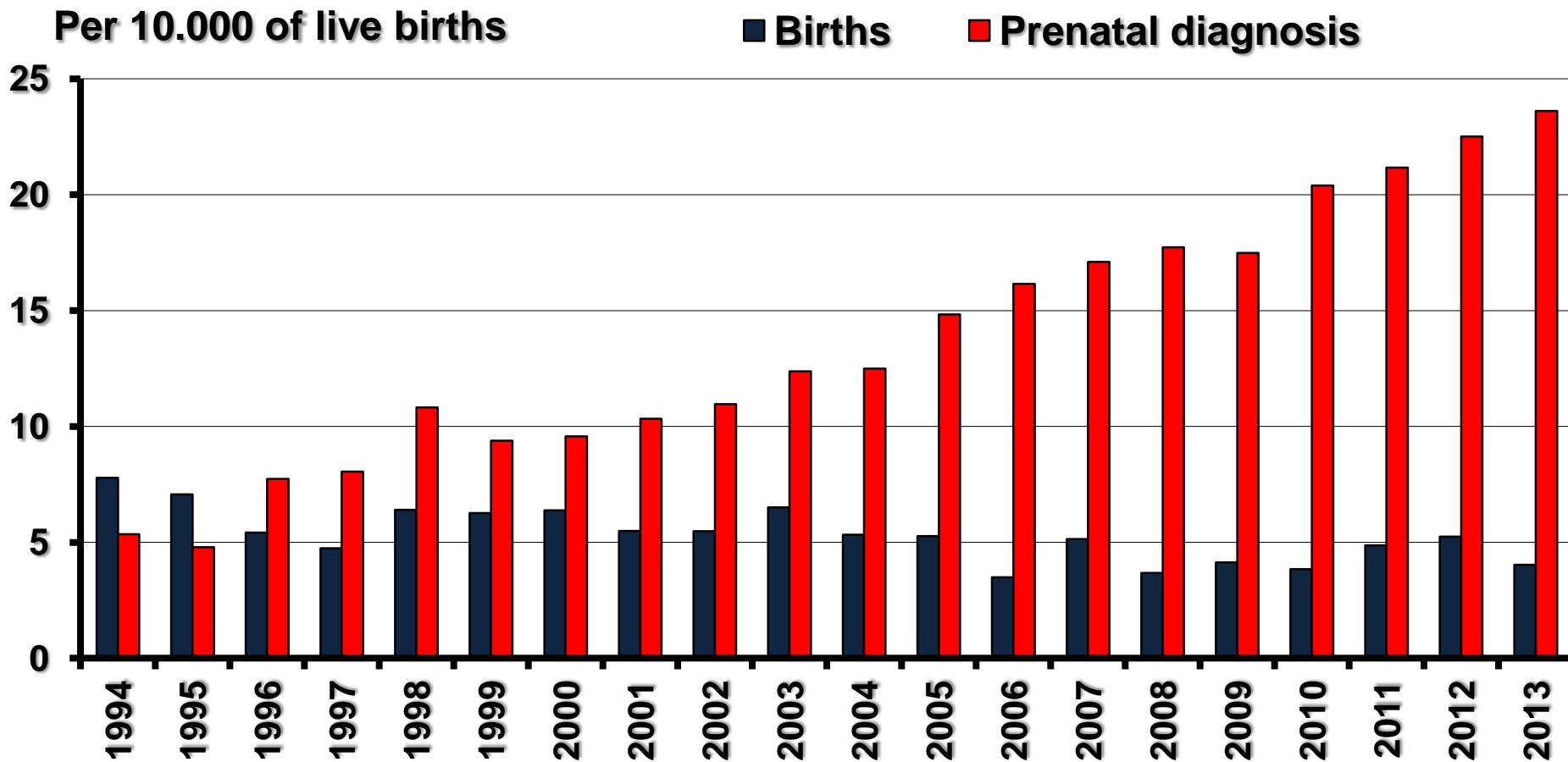
Screening



Proportion of screening programs in prenatal diagnosis (2013)



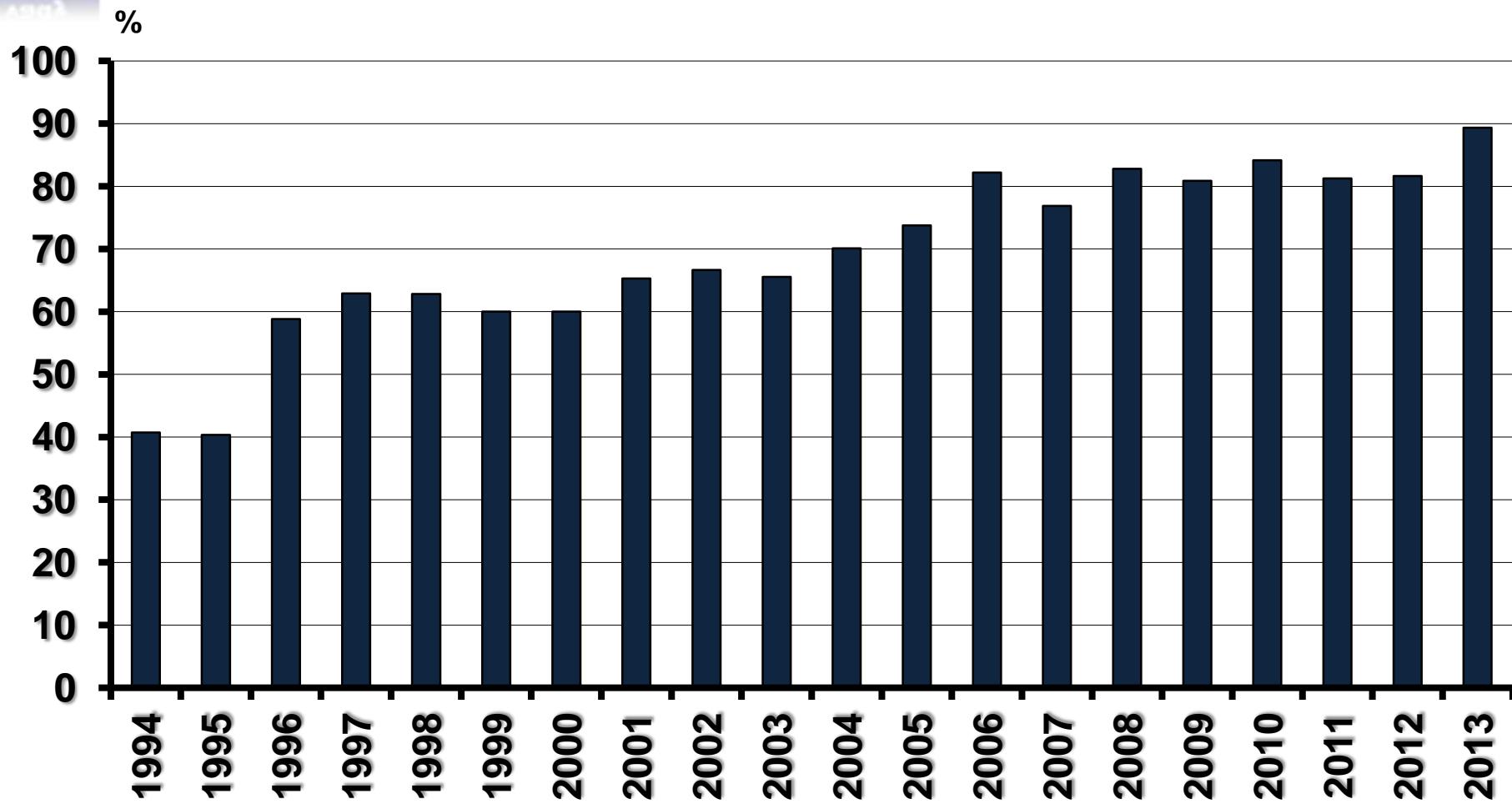
Down syndrome



Down syndrome – All cases in live births and prenatal diagnosis



Down syndrome



Down syndrome – relative number of prenatally diagnosed cases (%)

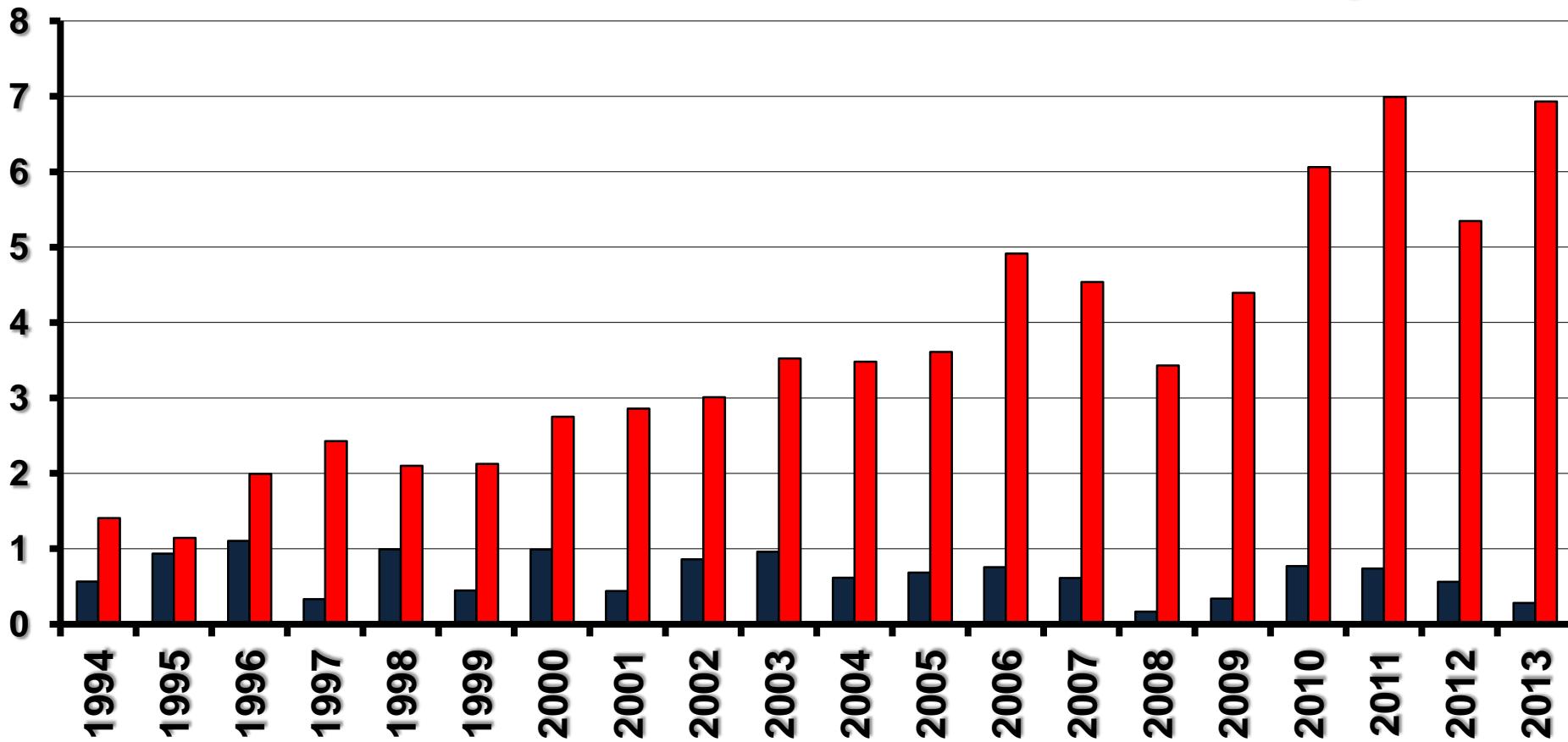


Edwards syndrome

Per 10.000 of live births

■ Births

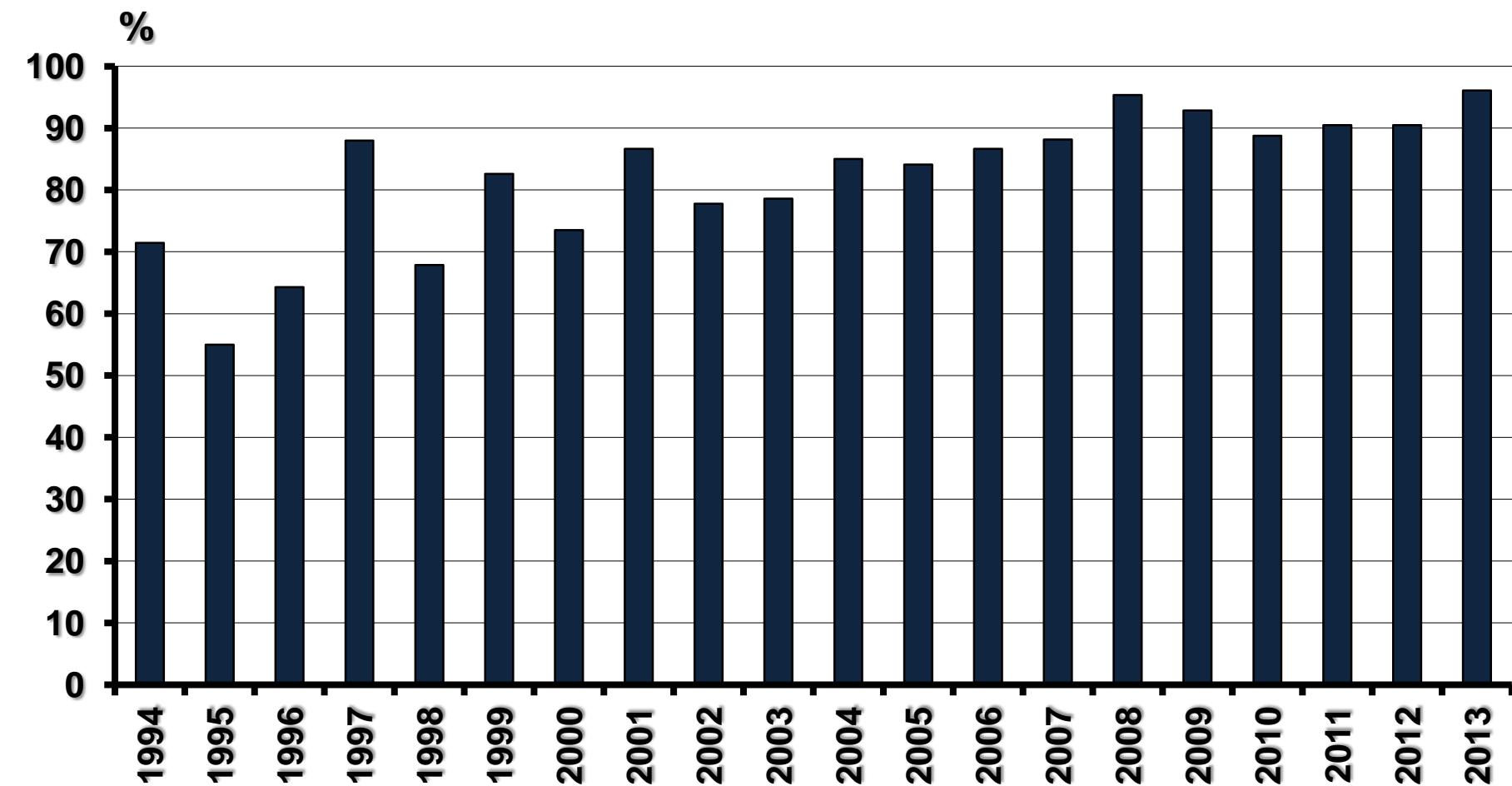
■ Prenatal diagnosis



Edwards syndrome – All cases in live births and prenatal diagnosis



Edwards syndrome



Edwards syndrome – relative number of prenatally diagnosed cases (%)

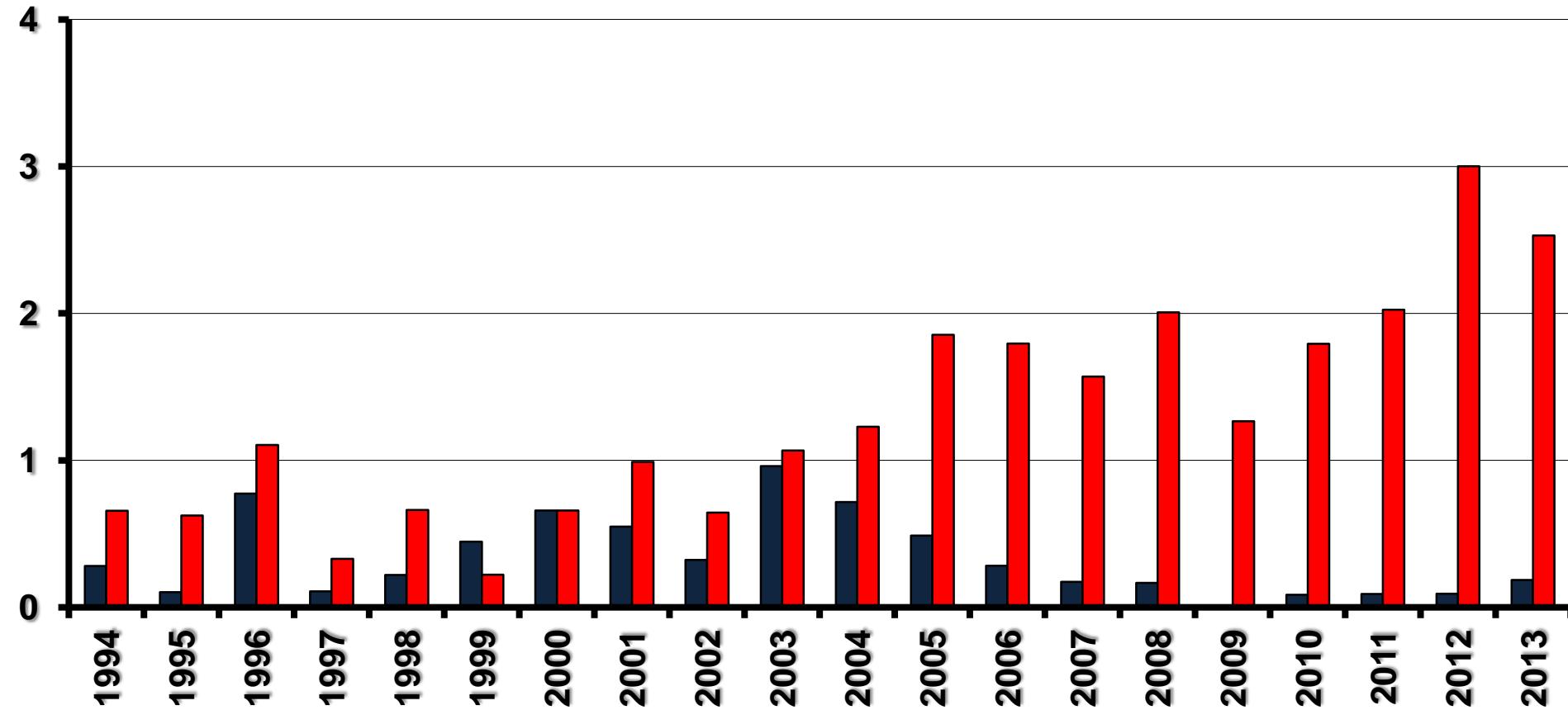


Patau syndrome

Per 10.000 of live births

■ Births

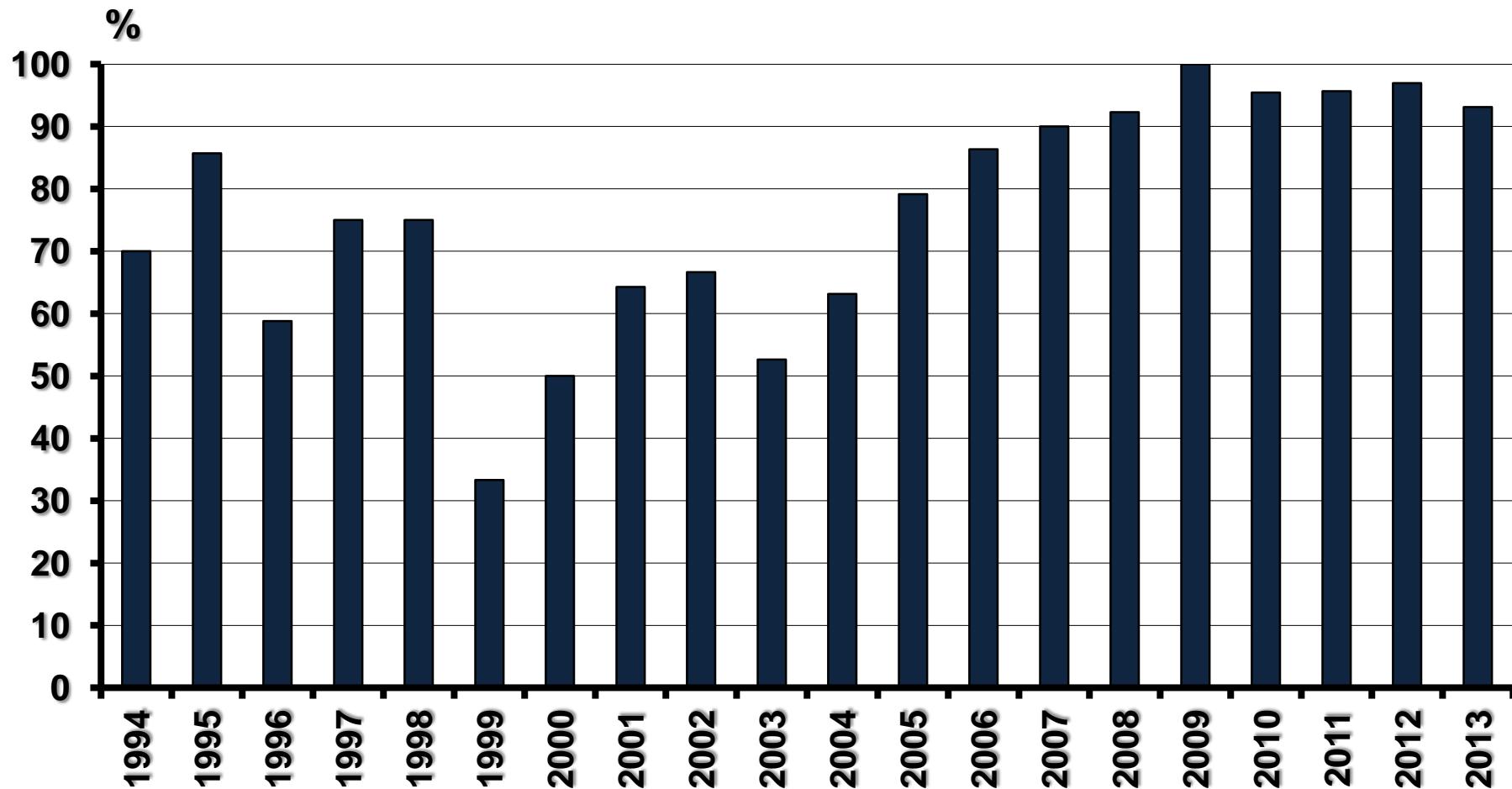
■ Prenatal diagnosis



Patau syndrome – All cases in live births and prenatal diagnosis



Patau syndrome

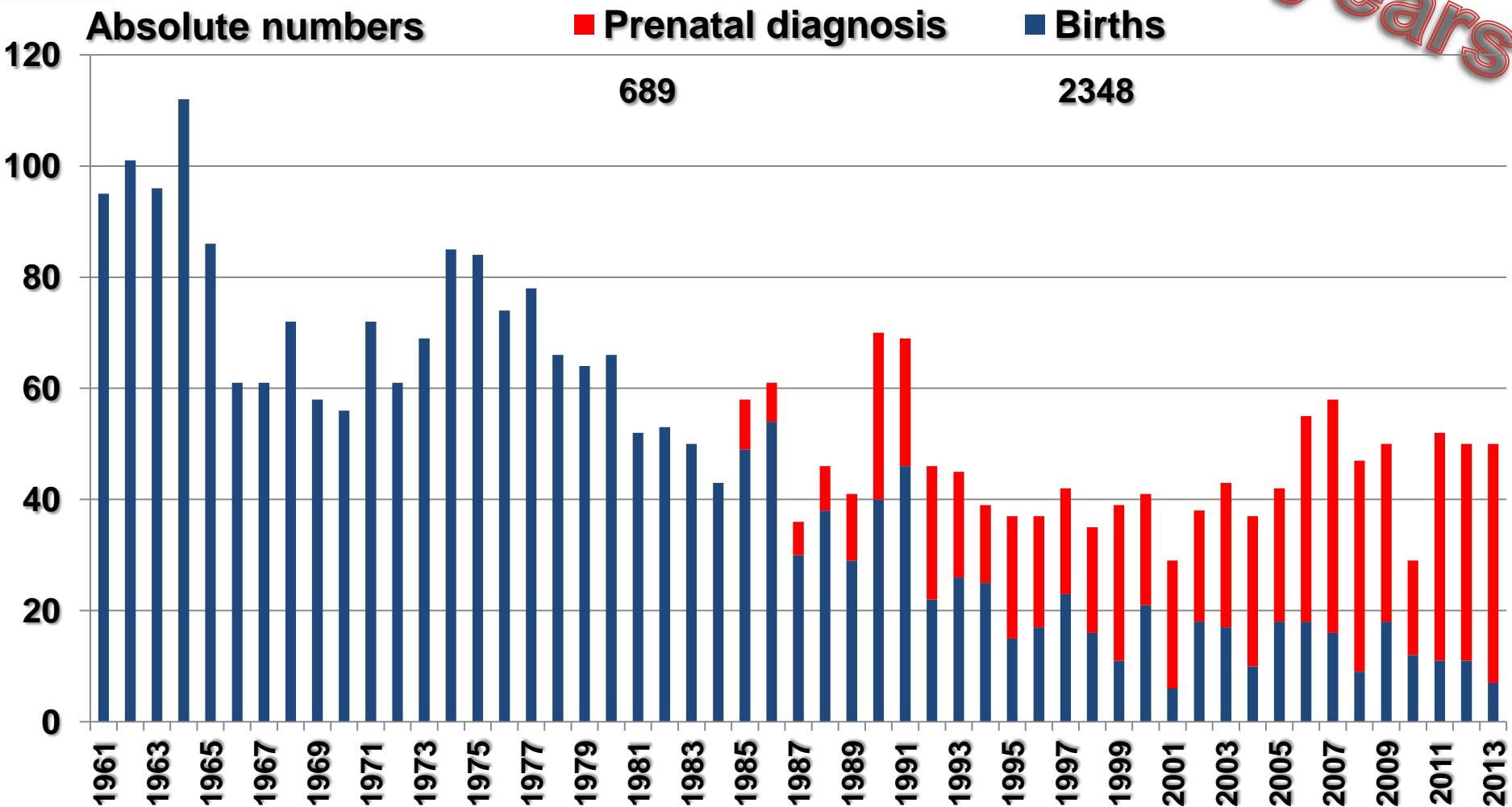


Patau syndrome – relative number of prenatally diagnosed cases (%)



Spina bifida

50+ years

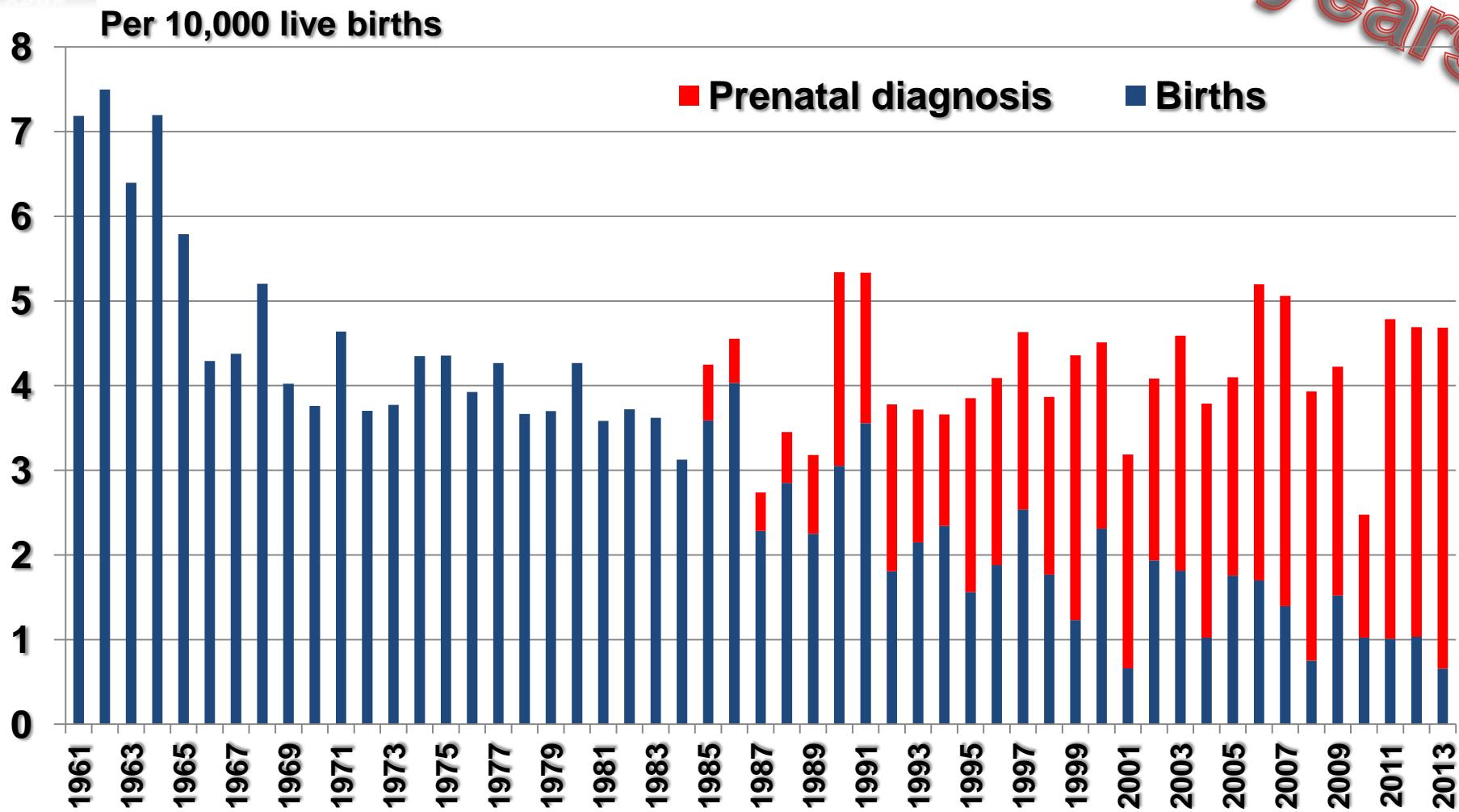


Spina bifida – All cases in live births and prenatal diagnosis



Spina bifida

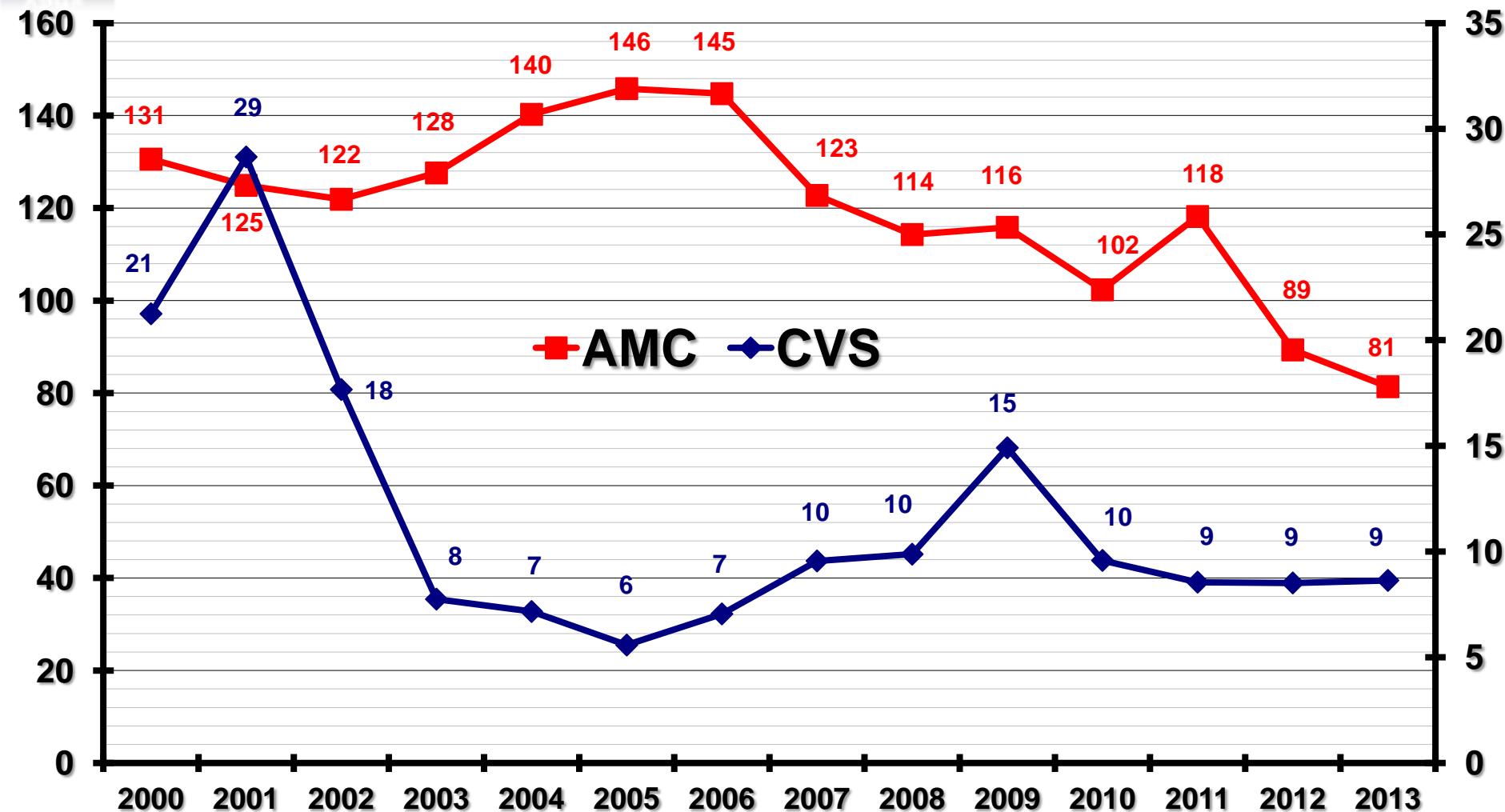
50+ years



Spina bifida – All cases in live births and prenatal diagnosis



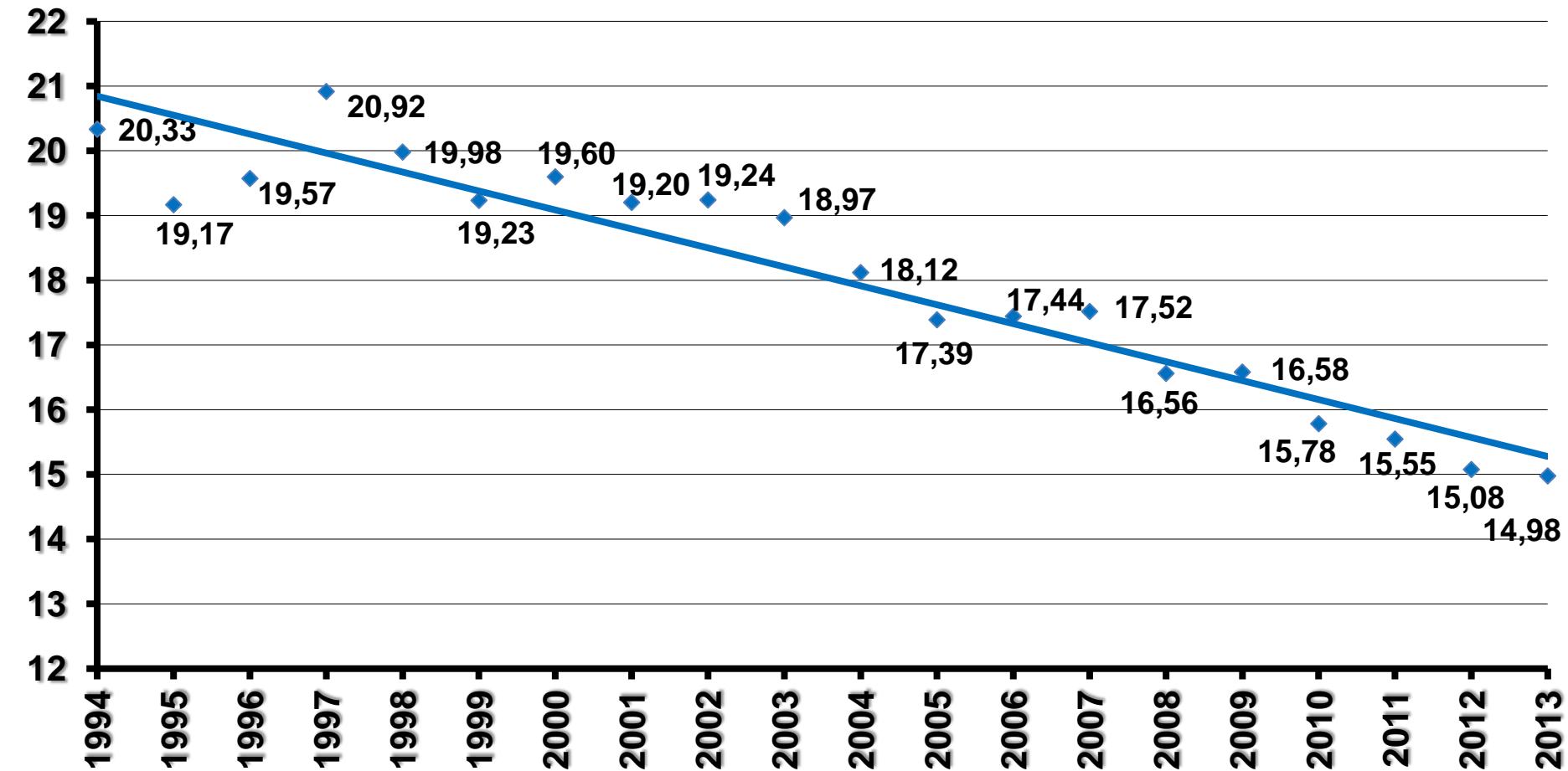
Effectiveness



Number of invasive procedures needed for one diagnosis of Down syndrome



Time of diagnosis



Average week of gestation at diagnosis of Down syndrome