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INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

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THE CENTRE OF THE INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH
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INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH (ICBDSR)

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INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

ANNUAL REPORT 2012

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Collaborative Research Projects

Multiple Congenital Anomalies (MCA), 2010

Monica Rittler (South America, ECLAMC)
Jorge López Camelo (South America, ECLAMC)

Introduction

For the year 2010, we received data from 4 programmes, for a total of 1873 reported cases, among 254,875 births (Table 1). Of these, 420 were reported as syndromes and 725 had at least two major, unrelated congenital anomalies, which is our current case definition of multiple congenital anomaly (MCA). Coding was done by Monica Rittler, statistical analyses, review and report writing by Jorge Lopez-Camelo.

Main findings and comments

This year, among the 47 defect groups, 45 were associated with an O/E ratio greater than 1. Eighteen of them reached statistical significance at a $p<0.001$ level, and are shown in Table 2.
A significant excess, at a $p< 0.001$ level, was found for 12 two-defects (Table 3) and for 2 three-defects combinations (Table 4).
For all comparisons, the data reported from 1992 through 2000, over 3,929,953 births were used as baseline.

Table 1: Cases of multiple congenital anomalies, by programme and number of defects (2010).

PROGRAMME	Births	Total cases Reported	Known etiology (syndromes)	< 2 major unrelated defects	2 Or + unrelatedr defects	Rate
Israel	43771	59	0	8	51	11.65
Japan	91082	829	273	320	236	25.91
Mexico	22341	31	8	1	22	9.847
South America	97681	954	139	387	428	43.82
TOTAL	254875	1873	420	716	737	28.91

Table 2: Association rates of defects, among cases with multiple congenital anomalies.

Code	Malformation	Obs	Exp	Excess	Poisson
290	Congenital heart defects	359	132.2	226.8	***
350	Urinary tract atresia/stenosis	87	45.4	41.6	***
120	Cleft lip with or without cleft palate	100	59.2	40.9	***
470	Spleen anomalies	38	3.8	34.2	***
070	Other CNS defects	56	25.2	30.8	***
020	Spina Bifida	48	19.9	28.1	***
320	Genitalia defects (ambiguous and other)	53	25.6	27.4	***
330	Kidney a/dysgenesis	48	22.2	25.8	***
190	Anorectal atresia/stenosis	86	61.1	24.9	***
090	Other eye anomalies	34	10.1	23.9	***
040	Hydrocephaly	67	45.1	21.9	***
410	Other limb reduction defects	34	14.2	19.8	***
340	Cystic kidneys	35	16.5	18.5	***
440	Club foot	85	68.0	17.0	***
130	Cleft Palate	51	35.9	15.1	***
210	Other gut atresia/stenosis	20	5.5	14.5	***
280	Other respiratory tract defects	24	10.3	13.7	***
110	Dysplastic ears	19	6.0	13.0	***
230	Other intestinal anomalies	21	10.0	11.0	
420	Polydactyly	58	47.0	11.0	
250	Omphalocele	37	26.2	10.8	
310	Hypospadias	33	22.3	10.8	
260	Diaphragmatic hernia	26	18.0	8.0	
430	Syndactyly	25	17.6	7.4	
460	Situs inversus	11	4.2	6.9	
220	Malrotation of gut	9	3.9	5.1	
240	Gastroschisis	13	8.0	5.0	
160	Craniostenosis	8	3.1	5.0	
380	Axial skeleton defects	38	33.3	4.7	
010	Anencephaly	13	9.1	3.9	
270	Tracheo-bronchial-larynx atresia/stenosis	5	1.4	3.6	
140	Other clefts and facial anomalies	14	10.6	3.4	
030	Encephalocele	15	11.7	3.3	
050	Microcephaly	24	21.1	2.9	
400	Preaxial limb reduction defects	17	14.1	2.9	
360	Exstrophy of cloaca	6	3.6	2.4	
180	Oesophageal atresia/stenosis	39	36.8	2.2	
060	Holoprosencephaly	10	8.3	1.7	
300	Vessel anomalies	2	0.5	1.5	
370	Sacrum anomalies	2	0.7	1.3	
100	Severe ear defects	32	31.1	0.9	
480	Other rare defects (Sacrococcigeal teratoma, sirenomelia)	4	3.2	0.8	
170	Pterygium colli, cystic hygroma	5	4.2	0.8	
200	Duodenal atresia (without annular pancreas)	7	6.7	0.3	
450	Ring constriction of limb(s)	0	0.0	0.0	
150	Choanal atresia/stenosis	3	3.1	0.0	
390	Transverse limb reduction defects	6	12.0	-6.0	
080	An/micropthalmia	12	19.5	-7.5	

****=p<0.001*

Table 3: Significant two-defect combinations.

Code	Malformation	Obs	Exp	Excess	Poisson
290350	Congenital Heart Defects + Urinary tract atresia/stenosis	46	14.7	31.28	***
290470	Congenital Heart Defects + Spleen anomalies	31	2.85	28.15	***
190290	Anorectal Atresia + Congenital Heart Defects	33	11.6	21.39	***
040290	Hydrocephaly + Congenital Heart Defects	27	9.08	17.92	***
130290	Cleft Palate + Congenital Heart Defects	24	7.78	16.22	***
070290	Other CNS defects + Congenital Heart Defects	22	7.13	14.87	***
250290	Omphalocele + Congenital Heart Defects	19	7.52	11.48	***
210290	Other gut atresia + Congenital Heart Defects	13	2.14	10.86	***
290460	Congenital Heart Defects + Situs inversus	11	1.23	9.77	***
320330	Genitalia defects + Kidney a/dysgenesis	12	2.85	9.15	***
330410	Kidney a/dysgenesis + Other limb reduction defects	8	0.65	7.35	***
230320	Other intestinal anomalies + Genitalia defects	5	0.39	4.61	***

Table 4: Significant two-defect combinations.

Code	Malformation	Obs	Exp	Excess	Poisson
290350420	CHD + Urinary tract atresia/stenosis + Polydactyly	7	0.65	6.35	***
290460470	CHD + Spleen anomalies + Situs inversus	6	0.13	5.87	***

Comments:

In 2010, only 4 programmes participated in the monitoring of multiples, as compared with between 7 and 8 during the last 6 years.

CHD were the anomalies most frequently found, as single defects, as well as among the 2 and 3-defects combinations.
A high rate of laterality defects is indicated by the second most frequently observed 2-defects combination (CHD + spleen anomalies), as well as among the 3-defects combinations with a significant excess.

According to the definitions, the following cases potentially exposed to three monitored teratogens were detected:

Retinoic acid: 1 case
SAM A0405910: Severe hydrocephaly. Left microtia with ear canal atresia. Right kidney agenesis. Double outlet of right ventricle.

Rubella: 2 cases
JAM 4059: Microphthalmia, ASD, microtia.
SAM A3317110: Bilateral cataracts, VSD, hydrops.

Thalidomide: 1 case
MEX 119002: Lumbar spina bifida, intercalary reduction defect of left lower limb.

This award honors the memory of Alessandra Lisi and recognizes a promising young researcher in the field of birth defects.
Alessandra Lisi was a young researcher at ICBDSR Centre from 2002 to her untimely death in 2006. Over the years, Alessandra's skill, work ethic, and grace made her an increasingly central part of the ICBDSR Centre. She died in a train accident (Rome Underground) on 17 October 2006, on her way to work at ICBDSR Centre.
We miss her beyond words, and honour her memory with a Prize for young outstanding researchers.

Eligibility requirements

- Active contribution to the epidemiology or surveillance of birth defects, preferably with an ICBDSR program
- Evidence of a promising research career as well as ongoing commitment to the field, as demonstrated for example by high quality publications in peer-reviewed journals, initiating or coordinating research projects, or obtaining funding for research in the field of birth defects epidemiology.
- Within seven years of the date of their last formal training in a field directly related to the disciplines of Birth Defects (e.g., degree conferral, postdoctoral fellowship, residency program, etc.).

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Nature of the award

The winner will receive a plaque and will be invited to give a presentation at the Annual and Scientific Meeting of the Clearinghouse, in order to present the work on which the Award was based and also to present the work he/she is doing at present.

Further information about the Prize application (award criteria, application process, deadline) are available at www.icbdsr.org

Past awardees

2012 The Award was not appointed, due to changes in the application procedures

2011 Narayan Iyer (UK Wales): "Outcome of fetuses with Turner syndrome: a 10 year congenital anomaly register based study". J Matern Fetal Neonatal Med. 2012 25(1):68-73.

2010 JannekeJentink (Northern Netherlands): "Valproic Acid Monotherapy in Pregnancy and Major Congenital Malformations" NEJM 2010,362:2185-93

2009 Somer Dowson (Western Australia): "Birth Defects in children with autism spectrum disorders: a population-based, nested case-control study", Am J Epidemiol 2009; 169(11):1296-1303

2008 Mikyong Shin (USA-Atlanta): "Prevalence of Spina Bifida among children and adolescents, Metropolitan Atlanta Birth Defects Res A ClinMolTeratol. 2008 Nov;82(11):748-54.

Synopsis of Contributing Monitoring Systems

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
Argentna	Hospital-based, National	2012	3 Days	500 grams	Not permitted
Australia:VBDR	Population-based Statewide	2002	Up to 18 years	20 weeks or 400 grams	Permitted, Reported
Australia: WARDA	Population-based, Statewide	2002	Up to 6 years	20 weeks or 400 grams	Permitted, Reported
Canada: Alberta-ACASS	Population-based Provincial	1996	1 year	20 weeks or 500 grams	Permitted, Reported
Canada British Columbia	Population-based Provincial	2001	No limit	At least 20 weeks or 500 grams	Permitted, Not reported
Canada: CCASS	Population-based National	1996	30 days	20 weeks or 500 grams	Permitted, Not reported
Chile-Maule: RRMC-SSM	Hospital-based Regional	2003	Hospital discharge	500 grams	Not permitted, Not reported
Colombia: BCMSP	Hospital-based Regional	2011	Hospital discharge	500 grams	Permitted only for a few selected cases, Not reported
Costa Rica: CREC	Population-based National	2003	3 days	20 weeks or 500 grams	Not permitted
Cuba: RECUMAC	Hospital-based, National	2003	Hospital discharge	500 grams	Permitted, Reported
Czech Republic	Population-based National	1974	Up to 15 years	Non-viable fetuses, 28 weeks or >1000 grams	Permitted, Reported
Finland	Population-based National	1974	1 year	22 weeks or 500 grams	Permitted, Reported
France-Rhône Alpes: REMERA	Population-based Regional	1974	1 year	22 weeks (*)	Permitted, Reported
France: Paris	Population-based Regional	1982	Hospital discharge	22 weeks	Permitted, Reported
France: Strasbourg	Population-based Regional	1982	2 years	22 weeks or 500 grams	Permitted, Reported
Germany: Saxony-Anhalt	Population-based (Federal State)	2001	Hospital discharge (almost first week of life) – up to 1 year	>/= 500 grams	Permitted, Reported
Hungary	Population-based National	1974	1 year	24 weeks or 500 grams (**)	Permitted, Reported
India: BDRI	Hospital-based, Regional	2010	1 year	24 weeks	Permitted, Reported
Iran: TROCA	Hospital-based Regional	2006	5 year	20 weeks or 400 grams	Permitted, Reported only for a few selected malformations
Ireland: Dublin	Population-based Regional	1997	5 years	24 weeks or 500 grams	Not permitted
Israel: IBDSP	Hospital-based Regional	1974	Hospital discharge 2-5 days	20weeks or 500 grams	Permitted, Reported

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
Italy-Tuscany:RTDC	Population-based Regional	1998	1 year	180 days (25 weeks + 5 days)	Permitted, Reported
Japan: JAOG	Hospital-based , National	1988	7 days	22 weeks	Permitted, Not reported
Malta: MCAR	Population-based National	2000	1 year	20 weeks	Not permitted, Not reported
Mexico: RYVEMCE	Hospital-based National	1980	72 hours	20 weeks or 500 grams	Not permitted
New Zealand	Population-based National	1979	No limit	20 weeks or 400 grams	Permitted, Reported
Northern Netherlands	Population-based Regional	1993	10 years	24 weeks	Permitted, Reported
Norway: MBRN	Population-based National	1974	Hospital discharge Lifelong for mortality (from 2002 1 year)	20 weeks or 300 grams	Permitted, Reported
Russia-Moscow Region: MRRCM	Population-based Regional	2001	1 year	28 weeks	Permitted, Reported
Slovak Republic	Population-based Regional	2003	1 year	28 weeks or 1000 grams	Permitted, Reported
Saudi Arabia	Hospital-based, National	2012	2 years	>/= 16 weeks	Permitted in few cases. Ony major malformations reported.
South America: ECLAMC	Hospital-based Multinational	1977	3 days	500 grams	Not permitted
Spain: ECEMC	Hospital-based National	1979	3 days (***)	24 weeks or 500 grams	Permitted, Not reported
Sweden	Population-based National	1974	28 days	22 weeks	Permitted, Reported
Ukraine: OMNI-Net Ukraine Birth Defects Program (Ukraine: OMNI-Net UBDP)	Population-based Regional	2001	1 year	>= 500 grams	Permitted, Only selected malformations reported
UK - Wales: CARIS	Population-based Regional	2005	1 year	24 weeks	Permitted, Reported
USA-Atlanta: MACDP	Population-based Regional	1974	6 years	20 weeks	Permitted, Reported
USA-California	Population-based Regional	1992	1 year	20 weeks	Permitted, Reported
USA-Texas: BDES	Population-based Regional	2004	1 year	20 weeks (****)	Permitted, Reported
USA-Utah UBDN	Population-based Regional	2005	No limit	20 weeks	Permitted, Reported

(*) Before 1993: 22 weeks; since 1993: 20 weeks

(**) Before 1998: 28 weeks; since 1998: 24 weeks

(***) For some cases a longer follow-up is performed

(****) Before 2001: 20 weeks. Since 2001: all stillbirths with documented birth defects included

ICBDSR Definitions of the Reported Malformations

The following definitions have been adopted by all monitoring systems except when indicated in the Table "Deviations from ICBDSR Definitions

1. Anencephaly: a congenital malformation characterized by the total or partial absence of the cranial vault, the covering skin, and the brain missing or reduced to small mass. Includes: craniorachischisis and infants with iniencephaly and other neural tube defects as encephalocele or open spina bifida, when associated with anencephaly.Excludes: acephaly, that is, absence of head observed in amorphous acardiac twins.

2. Spina bifida: a family of congenital malformation defects in the closure of the spinal column characterized by herniation or exposure of the spinal cord and/or meninges through an incompletely closed spine. Includes: meningocele, meningomyelocele, myelocele, myelomeningocele, rachischisis. Spina bifida is not counted when present with anencephaly. Excludes: spina bifida occulta, sacrococcygeal teratoma without dysraphism .

3. Encephalocele: a congenital malformation characterized by herniation of the brain and/ or meninges through a defect in the skull. Encephalocele is not counted when present with spina bifida.

4. Microcephaly: a congenitally small cranium, defined by an occipito frontal circumference (OFC) 3 standard deviation below the age and sex appropriate distribution curves. [If using a different definition or cut off point (e.g., 2 standard deviations), report but specify criteria]. Excludes: microcephaly associated with anencephaly or encephalocele.

5. Holoprosencephaly: a congenital malformation of the brain, characterized by various degrees of incomplete lobation of the brain hemispheres. Olfactory nerve tract may be absent. Holoprosencephaly includes cyclopia, ethmocephaly, cebocephaly, and premaxillary agenesis.

6. Hydrocephaly: a congenital malformation characterized by dilatation of the cerebral ventricles, not associated with a primary brain atrophy, with or without enlargement of the head, and diagnosed at birth. Not counted when present with encephalocele or spina bifida. Excludes: macrocephaly without dilatation of ventricular system, skull of macerated fetus, hydranencephaly, holoprosencephaly, and postnatally acquired hydrocephalus.

7. Anophthalmos/microphthalmos: apparently absent or small eyes. Some normal adnexal elements and eyelids are usually present. In microphthalmia, the corneal diameter is usually less than 10 mm. and the antero posterior diameter of the globe is less than 20 mm.

8. Anotia/microtia: a congenital malformation characterized by absent parts of the pinna (with or without atresia of the ear canal) commonly expressed in grades (I IV) of which the extreme form (grade IV) is anotia, absence of pinna. Excludes: small, normally shaped ears, imperforate auditory meatus with a normal pinna, dysplastic and low set ears.

9. Transposition of great vessels: a cardiac defect where the aorta exits from the right ventricle and the pulmonary artery from the left ventricle, with or without other cardiac defects. Includes: double outlet ventricle and the so called corrected transposition.

10. Tetralogy of Fallot: a condition characterized by ventricular septal defect, overriding aorta, infundibular pulmonary stenosis, and often right ventricular hypertrophy.

11. Hypoplastic left heart syndrome: a cardiac defect with a hypoplastic left ventricle, associated with aortic and/or mitral valve atresia, with or without other cardiac defect.

12. Coarctation of the aorta: an obstruction in the descending aorta, almost invariably at the insertion of the ductus arteriosus

13. Choanal atresia, bilateral: congenital obstruction (membraneous or osseous) of the posterior choana or choanae. Excludes: choanal stenosis and congestion of nasal mucosa.

14. Cleft palate without cleft lip: a congenital malformation characterized by a closure defect of the hard and/or soft palate behind the foramen incisivum without cleft lip. Includes: submucous cleft palate. Excludes: cleft palate with cleft lip, cleft uvula, functional short palate, and high narrow palate.

15. Cleft lip with or without cleft palate: a congenital malformation characterized by partial or complete clefting of the upper lip, with or without clefting of the alveolar ridge or the hard palate. Excludes: midline cleft of upper or lower lip and oblique facial fissure (going towards the eye).

16. Oesophageal atresia/stenosis: a congenital malformation characterized by absence of continuity or narrowing of the esophagus, with or without tracheal fistula. Includes: tracheoesophageal fistula with or without mention of atresia or stenosis of oesophagus

17. Small intestine atresia/stenosis: complete or partial occlusion of the lumen of a segment of the small intestine. It can involve a single area or multiple areas of the jejunum or ileum. Excludes: duodenal atresia.

18. Anorectal atresia/stenosis: a congenital malformation characterized by absence of continuity of the anorectal canal or of communication between rectum and anus, or narrowing of anal canal, with or without fistula to neighboring organs. Excludes: mild stenosis which does not need correction, and ectopic anus.

19. Undescended testis: bilateral undescended testes in at term newborn or at least unilateral undescended testis in males more than 1 year of age. Excludes: retractile testis.

20. Hypospadias: a congenital malformation characterized by the opening of the urethra on the ventral side of the penis, distally to the sulcus. Includes: penile, scrotal, and perineal hypospadias. Excludes: glandular or first degree hypospadias and ambiguous genitalia (intersex or pseudohermaphroditism).

21. Epispadias: a congenital malformation characterized by the opening of the urethra on the dorsal surface of the penis. Not counted when part of exstrophy of the bladder.

22. Indeterminate sex: genital ambiguity at birth that does not readily allow for phenotypic sex determination. Includes: male or female, true or pseudohermaphroditism.

23. Renal agenesis: a congenital malformation characterized by complete absence of kidneys bilaterally or severely dysplastic kidneys.

24. Cystic kidney: a congenital malformation characterized by multiple cysts in the kidney. Includes: infantile polycystic kidney, multicystic kidney, other forms of cystic kidney and unspecified cystic kidney. Excludes: single kidney cyst.

25. Bladder exstrophy: complex malformation characterized by a defect in the closure of the lower abdominal wall and bladder. Bladder opens in the ventral wall of the abdomen between the umbilicus and the symphysis pubis. It is often associated with epispadias and structural anomalies of the pubic bones.

26. Polydactyly, preaxial: extra digit(s) on the radial side of the upper limb or the tibial side of the lower limb. It can affect the hand, the foot, or both.

27. Limb reduction defects: a congenital malformation characterized by total or partial absence or severe hypoplasia of skeletal structures of the limbs. Includes: femoral hypoplasia. Excludes: mild hypoplasia with normal shape of skeletal parts, brachydactyly, finger or toe reduction directly associated with syndactyly, general skeletal dysplasia and sirenomelia.

28. Diaphragmatic hernia: a congenital malformation characterized by herniation into the thorax of abdominal contents through a defect of the diaphragm. Includes: total absence of the diaphragm. Excludes: hiatus hernia, eventration and phrenic palsy.

29. Abdominal wall defects: cases specified as omphalocele and/or gastroschisis plus unspecified cases.

30. Omphalocele: a congenital malformation characterized by herniation of abdominal contents through the umbilical insertion and covered by a membrane which may or may not be intact. Excludes: gastroschisis (para umbilical hernia), a or hypoplasia of abdominal muscles, skin covered umbilical hernia.

31. Gastroschisis: a congenital malformation characterized by visceral herniation usually through a right side abdominal wall defect to an intact umbilical cord and not covered by a membrane. Excludes: a or hypoplasia of abdominal muscles, skin covered umbilical hernia, omphalocele.

32. Prune belly sequence: a complex congenital malformation characterized by deficient abdominal muscle and urinary obstruction/distension. It can be caused by urethral obstruction secondary to posterior urethral valves or urethral atresia. In the affected fetus the deficiency of the abdominal muscle may not be evident. It can be associated with undescended testes, clubfoot, and limb deficiencies.

33. Trisomy 13: a congenital chromosomal malformation syndrome associated with extra chromosome 13 material. Includes: translocation and mosaic trisomy 13.

34. Trisomy 18: a congenital chromosomal malformation syndrome associated with extra chromosome 18 material.
Includes: translocation and mosaic trisomy 18

35. Down syndrome: a congenital chromosomal malformation syndrome characterized by a well known pattern of minor and major anomalies and associated with excess chromosomal 21 material. Includes: trisomy mosaicism and translocations of chromosome 21

Deviations from the ICBDSR Definitions by Registry

	Encephalocele	Microcephaly	Arhinencephaly / Holoprosencephaly	Hydrocephaly	Anophthalmos / Microphthalmos	Anotia	Transposition of great vessels	Tetralogy of Fallot	Choanal atresia, bilateral	Cleft palate without cleft lip	Cleft lip with or without cleft palate	Oesophageal atresia / stenosis	Small intestine atresia / stenosis	Anorectal atresia / stenosis	Undescended testis	Hypospadias	Epispadias	Indeterminate sex	Renal agenesis	Cystic kidney	Polydactyly, preaxial	Limb reduction defects	Prune belly sequenze	Trisomy 13	Trisomy 18	Down syndrome
Argentina: RENAC	1	3			2																					2
Australia: VBDR									11	14						25					35					
Australia: WARDA									11							25			28		35					
Canada: Alberta		2			2	7	8		11,12							25					35					2
Canada: British Columbia	1	2	4	6	2	7	8	10	11,12	13	15		18,19			25	25,26	27	28	30	35	37		2	2	2
Canada: National	1	2		6	2				11,12	14			18	21	23	25	26		28	31	35		40	2	2	2
"Chile-Maule: RRMC-SSM"	1	2		24					11		15, 16													2	2	2
Colombia: BCMSP																25										
Costa Rica: CREC				6			9		11,12								26	27	28	31	35			2	2	2
Cuba: RECUMAC	1	2		6	2	7			11	14	15		18			25	26	27	28	32	35	37		2	2	2
Czech Republic																25					35					
Finland		2			2	42	8		11,12							25		27		32				2	2	2
France: Central East																25										2
France: Paris																25										
France: Strasbourg		2			2		9						18						28,29	30						
Germany: Saxony-Anhalt		2,3					9		11				19			25				32	36	38		2	2	2
Hungary	1	2			2		9									25	26				35	38,39		2	2	2
Iran: TRoCA	1		4	6			9						18	21							35	38				2
Ireland: Dublin		2			2				11				18,19		24	25	26				35			2	2	2
Israel: IBDMS							8									25				33						
Italy: BDRCAM																								2	2	2
Italy: IMER																25					35					
Italy: North East			5		2					13	15	17	18,20	22					29		35					2
Italy-Tuscany: RTDC							8																			
Italy-Lombardy:CMLR		3							11				18			25			28		35					
Japan: JAOG		2			2															31						
Malta		2			2		9		11									27		31	35	37		2	2	2
Mexico: RYVEMCE		2			2				11,12				18					27	28	30	35			2	2	2
New Zealand					2											25	26							2	2	2
Northern Netherlands															24	25					35					
Norway																										
Russia: Moscow region		2			2		9						18			25		27	28	31	35			2	2	2
Saudi Arabia Kingdom: MSD-BDR			3					9						19,29		23	25			29	32,33	35	37,39			2
Slovak Republic											15					25					35					2
South America: ECLAMC																25										
Spain: ECEMC		3			2													27				37				2
Sweden		2			2				11							25			28	32						2
Ukraine		41		6			9				16							27						2	2	2
UK - Wales: CARIS	1	2			2	7	8								24	25								2	2	2
USA: Atlanta									12		16															
USA: California									11	13	16															
USA: Texas						7			11,12		15,16							27								
USA-Utah UBDN		43													24			24			24			2	2	2

1 = when present with spina bifida counted
2 = clinical diagnosis included
3 = OCF below 3rd percentile
4 = there may be other defects with the same code
5 = only cyclopia included
6 = hydranencephaly included
7 = absence of auricle
8 = double outlet right ventricle excluded
9 = all kind of transposition included
10 = Trilogy of Fallot included
11 = unilateral cases included
12 = stenosis included
13 = submucous cleft palate excluded
14 = cleft uvula included
15 = midline and oblique facial clefts included
16 = clefts of the alveolar ridge without cleft lip included
17 = stenosis excluded
18 = doudenal atresia included
19 = doudenal stenosis excluded
20 = intestinal stenosis excluded
21 = large intestine atresia/stenosis included
22 = stenosis excluded
23 = no gestational age information (cases at all gestational age collected)
24 = registered when it is combined with other defects
25 = all types included
26 = epispadias counted with hypospadias
27 = genital ambiguity and absent genitalia included
28 = unilateral defects included
29 = severely dysplastic kidneys excluded
30 = single cyst included
31 = all kind of cystic kidney included
32 = all cystic kidneys are included except for single renal cysts
33 = AR polycystic kidney excluded
34 = some autosomalrecessive polycystyc kidneys are not excluded
35 = any type of polydactyly included
36 = polysyndactyly preaxial excluded
37 = any hypoplasia of skeletal limb structures included except branchydactyly and hypoplasia as part of skeletal dysplasia
38 = any hypoplasia of skeletal structures included
39 = sirenomelia included
40 = Prune belly sequence counted with Total abdominal wall defects
41 = includes congenital and postnatally diagnosed microcephaly (up to 1 year of age)
42 = anotia and microtia are reported without specification
43 = Isolated cases not reported (from January 1, 2011)

Argentina; RENAC
National Registry of Congenital Anomalies of Argentina

History:
The Programme started in november 2009 in 4 provinces of Argentina as a hospital-based registry. Since then it has grown in size and coverage, reaching all 24 provinces of the country. It was created with two main objectives: the classical one of generating epidemiological knowledge about distribution and determinants of birth defects, but also with the objective of improving care of affected newborns.

Size and coverage:
The number of participating hospitals has grown from 4 in 2009 to 120 at the present time. RENAC covers 300,000 annual births, aproximately 70% of births in the public sector and 40% of births of the whole country. The registry works by now in public maternity hospitals with more than 1,000 annual births per year. In the next years it will includes maternity hospitals from de the non-public sector

Legislation and funding:
The Programme is funded by the National Center of Medical Genetics (CNGM) and the Programme of Medical Genetics National Network, under the National Ministry of Health. Information is disseminated to the stakeholders, including the participating neonatologists who feel empowered when using locally their own processed data. The dissemination is performed through a printed annual report, an annual meeting funded by the NMoH (attended by neonatologists, members of other health programs, clinical geneticists and authorities); and the electronic sending of reports to the stakeholders.

Sources of ascertainment:
Reporting is made by collaborating neonatologists at the maternity hospitals.The detection period lasts until discharge from the hospital, including live birth and stillbirths (with more than 500 grams) with major morphological birth defects. The neonatologists describe birth defects in an open field with a verbatim description. Each month, they send data to the Coordination through a restricted access website (a forum platform) that allows data sending, resolution of operational issues and discussion of clinical cases. Forum interaction allows social cohesion among all participants who feel themselves as members of the same team. To achieve a high and homogeneous coding quality, coding is performed by medical geneticists of the Coordination. To allow comparisons with other sources we use the ICD-10 with the British Pediatrics Association modification

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Argentina: RENAC, 2010

Live births (LB)	39,144
Stillbirths (SB)	443
Total births	39,587
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	8	5	nr	3.28
Spina bifida	24	0	nr	6.06
Encephalocele	11	0	nr	2.78
Microcephaly	13	1	nr	3.54
Holoprosencephaly	6	0	nr	1.52
Hydrocephaly	54	1	nr	13.89
Anophthalmos	3	0	nr	0.76
Microphthalmos	5	0	nr	1.26
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	1	0	nr	0.25
Microtia	13	1	nr	3.54
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	3	0	nr	0.76
Tetralogy of Fallot	12	1	nr	3.28
Hypoplastic left heart syndrome	8	0	nr	2.02
Coarctation of aorta	3	1	nr	1.01
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	13	0	nr	3.28
Cleft lip with or without cleft palate	46	1	nr	11.87
Oesophageal atresia/stenosis with or without fistula	12	0	nr	3.03
Small intestine atresia/stenosis	15	0	nr	3.79
Anorectal atresia/stenosis	10	1	nr	2.78
Undescended testis (36 weeks of gestation or later)	6	0	nr	1.52
Hypospadias	2	0	nr	0.51
Epispadias	0	0	nr	0.00
Indeterminate sex	16	4	nr	5.05
Renal agenesis	4	1	nr	1.26
Cystic kidney	19	2	nr	5.30
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	6	1	nr	1.77
Total Limb reduction defects (include unspecified)	22	1	nr	5.81
Transverse	13	0	nr	3.28
Preaxial	6	1	nr	1.77
Postaxial	3	0	nr	0.76
Intercalary	0	0	nr	0.00
Mixed	3	0	nr	0.76
Unspecified	6	0	nr	1.52
Diaphragmatic hernia	5	0	nr	1.26
Omphalocele	19	2	nr	5.30
Gastroschisis	32	2	nr	8.59
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	4	1	nr	1.26
Trisomy 13	2	0	nr	0.51
Trisomy 18	4	0	nr	1.01
Down syndrome, all ages (include age unknown)	81	3	nr	21.22
<20	12	0	nr	nr
20-24	10	1	nr	nr
25-29	11	0	nr	nr
30-34	9	1	nr	nr
35-39	21	1	nr	nr
40-44	17	0	nr	nr
45+	1	0	nr	nr
unknown	0	0	nr	---

nr = not reported

Australia: WARDA
Western Australian Register of Developmental Anomalies

History:
The Register is located in a teaching obstetric hospital. In January, 2011, notification to the Register became statutory and the Western Australian Cerebral Palsy Register was combined with the Western Australian Birth Defects Registry, to become the Western Australian Register of Developmental Anomalies (WARDA). The objectives of the Register remain the same: to establish how often birth defects and cerebral palsy occur, to conduct research into their causes and prevention, to provide health professionals and the public with information about birth defects and cerebral palsy, and to monitor and evaluate screening, treatment and prevention programs.

Size and coverage:
Population-based in the state of Western Australia. 30,000 birth a year, ~6% reported with a birth defect; 2.5 per 1000 with cerebral palsy. Birth defects diagnosed prenatally and up to the age of 6 years, in stillbirths, terminations of pregnancy and livebirths are included. Cerebral palsy of all types and severity, including postnatal causes and diagnosed up to 5 years of age is now also included. The Register covers births from 1980 for birth defects and from 1956 for cerebral palsy.

Legislation and funding:
Following a period of short term funding from both Federal and State sources, the Register is now wholly funded by the Western Australian Department of Health. Notification to the Register by medical practitioners was made statutory in January 2011.

Sources of ascertainment:
Statutory sources: Midwives' Notification of Birth Forms (all births over 20 weeks gestation), Death Certificates (perinatal, infant and childhood); Hospital Morbidity (all hospital discharges in Western Australia); medical practitioners and hospitals. The latter two sources include notifications from maternity and paediatric hospitals, obstetricians, paediatricians, orthopaedic surgeons, cytogenetic laboratories, pathology services (including prenatal screening services), child development services, ultrasound practices and genetic services.

Exposure information:
No exposure information is routinely collected.

Background information:
The data on WARDA are routinely linked to the linked dataset of all births, deaths and hospital admissions for Western Australia. This linkage provides information on variables such as maternal and paternal age, labour and delivery data, and maternal illnesses, for both cases of developmental anomalies (numerators) and all births in Western Australia (denominators). Data from the Register are provided to the National Perinatal Statistics and Epidemiology Unit and the Australia Cerebral Palsy Register. Further information is available on the WARDA website: http://kemh.health.wa.gov.au/services/register_developmental_anomalies/

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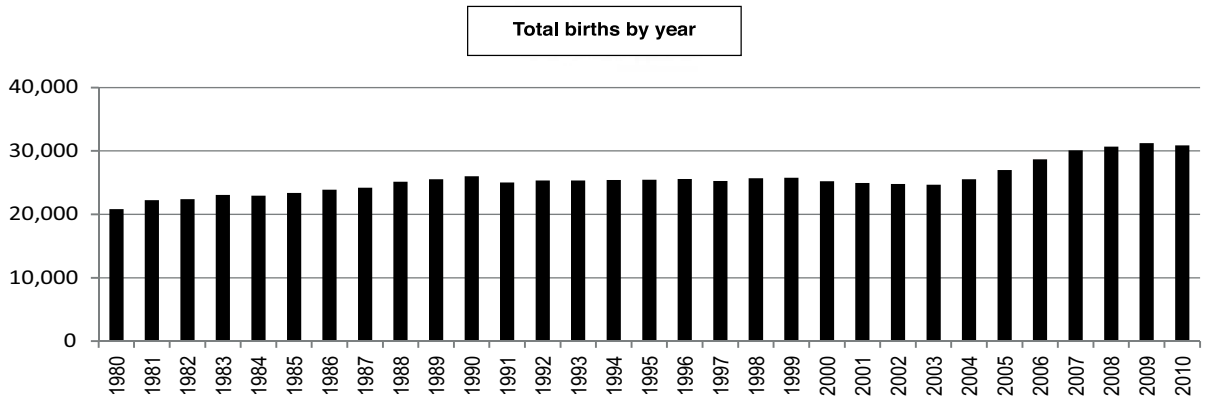
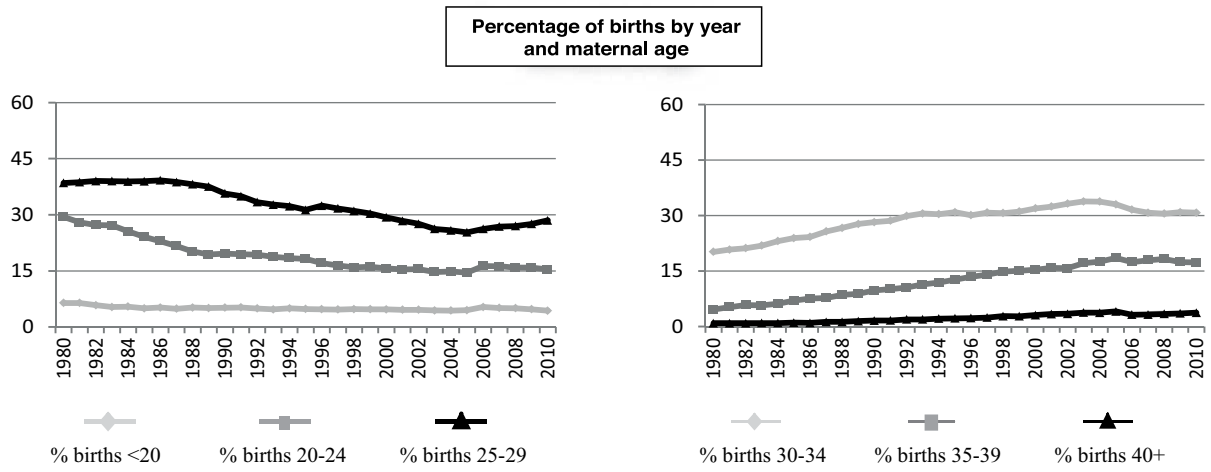
Australia: WARDA





Terminations of pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	46	92.0	Cystic kidney	24	29.6
Spina bifida	34	64.2	Limb reduction defects	29	50.0
Encephalocele	14	77.8	Diaphragmatic hernia	8	29.6
Holoprosencephaly	9	60.0	Omphalocele	34	85.0
Hydrocephaly	38	60.3	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	15	62.5	Trisomy 13	25	86.2
Cleft palate without cleft lip	10	10.6	Trisomy 18	58	78.4
Cleft lip with or without cleft palate	17	17.0	Down syndrome	179	66.3
Renal agenesis	21	47.7			

Total ToPs with births defects = 644 (Ratio ToPs/Births: 6.94 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: WARDA, 2010

Live births (LB)	30,660
Stillbirths (SB)	216
Total births	30,876
Number of terminations of pregnancy (ToP) for birth defects	228

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	10	3.56
Spina bifida	5	0	15	6.48
Encephalocele	1	0	3	1.30
Microcephaly	8	0	0	2.59
Holoprosencephaly	0	0	1	0.32
Hydrocephaly	6	1	12	6.15
Anophthalmos	0	0	0	0.00
Microphthalmos	3	0	1	1.30
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.97
Microtia	3	0	0	0.97
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	4	1	2	2.27
Tetralogy of Fallot	9	1	3	4.21
Hypoplastic left heart syndrome	2	0	5	2.27
Coarctation of aorta	13	0	0	4.21
Choanal atresia, bilateral	1	0	1	0.65
Cleft palate without cleft lip	25	0	0	8.10
Cleft lip with or without cleft palate	23	0	3	8.42
Oesophageal atresia/stenosis with or without fistula	5	0	1	1.94
Small intestine atresia/stenosis	10	0	2	3.89
Anorectal atresia/stenosis	19	0	2	6.80
Undescended testis (36 weeks of gestation or later)	62	0	0	20.08
Hypospadias	74	0	0	23.97
Epispadias	1	0	0	0.32
Indeterminate sex	0	0	0	0.00
Renal agenesis	9	1	6	5.18
Cystic kidney	15	1	6	7.13
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	31	0	1	10.36
Total Limb reduction defects (include unspecified)	6	1	11	5.83
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	4	1	3	2.59
Omphalocele	1	1	8	3.24
Gastroschisis	10	0	0	3.24
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	4	1.94
Trisomy 18	3	3	19	8.10
Down syndrome, all ages (include age unknown)	29	1	68	31.74
<20	0	0	0	0.00
20-24	1	0	2	6.31
25-29	4	0	10	15.92
30-34	9	0	13	23.18
35-39	6	0	23	54.30
40-44	9	1	19	261.50
45+	0	0	1	222.22
unknown	0	0	0	---

nr = not reported

Australia: WARDA, Previous years rates 1980 - 2010

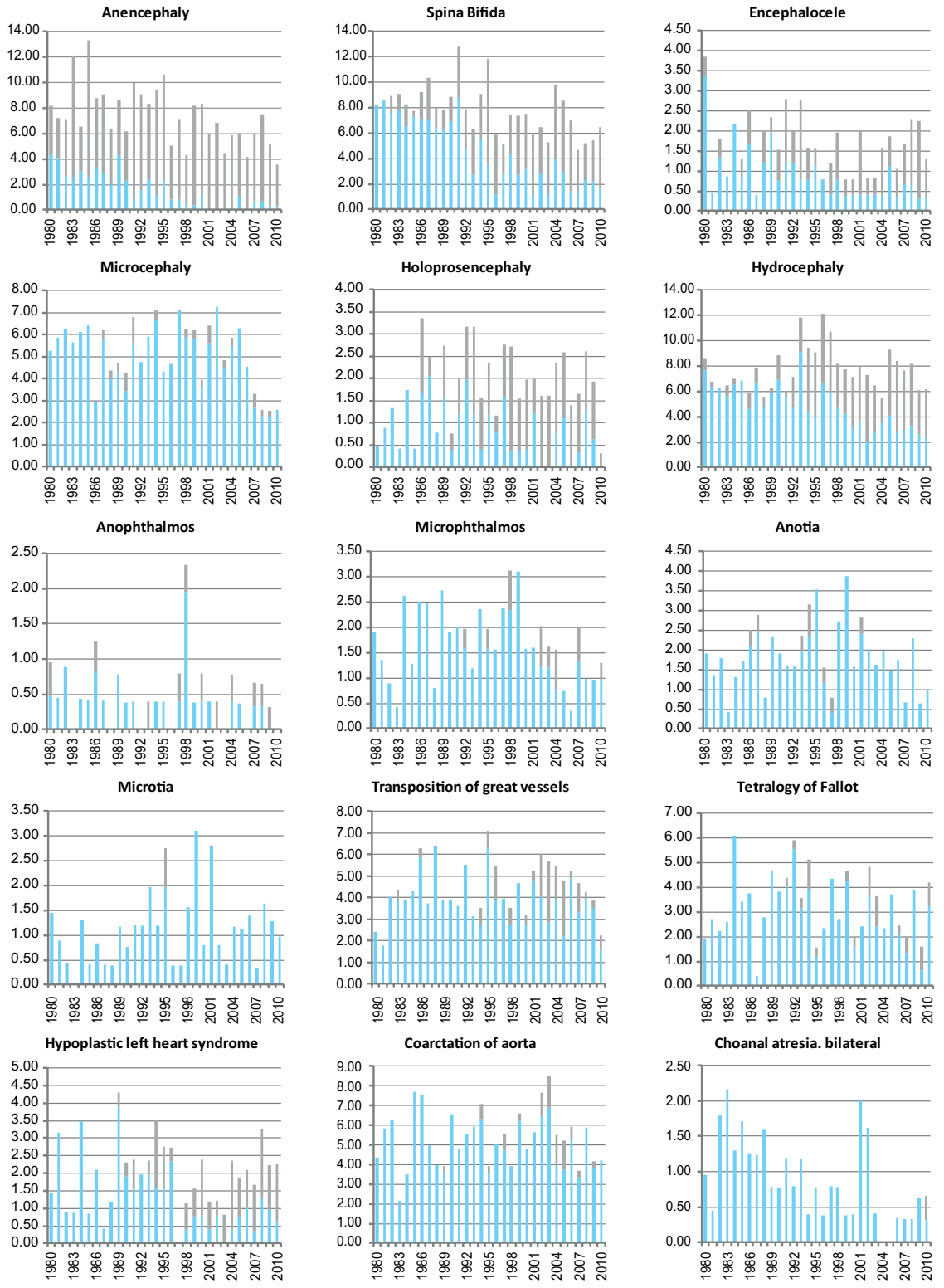
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**20,815**	**114,004**	**124,813**	**126,534**	**127,524**	**126,924**	**151,509**
Anencephaly	8.17	9.30	7.77	9.48	6.59	5.83	5.28
Spina bifida	8.17	8.51	8.81	9.56	6.67	7.25	5.74
Encephalocele	3.84	1.32	1.76	2.13	1.10	1.42	1.72
Microcephaly	5.28	6.05	4.49	5.77	5.65	6.15	3.10
Holoprosencephaly	0.48	0.96	2.00	2.45	2.04	2.05	1.58
Hydrocephaly	8.65	6.67	6.89	8.69	9.17	7.33	7.26
Anophthalmos	0.96	0.44	0.56	0.32	0.86	0.39	0.33
Microphthalmos	1.92	1.32	2.08	1.90	2.35	1.50	1.12
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.07
Anotia	1.92	1.32	2.08	2.45	2.12	1.97	1.25
Microtia	1.44	0.61	0.72	1.66	1.25	1.26	1.12
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.07
Transposition of great vessels	2.40	3.68	4.81	4.58	4.16	5.44	4.03
Tetralogy of Fallot	1.92	3.42	3.12	4.11	3.22	3.39	2.84
Hypoplastic left heart syndrome	1.44	1.84	2.08	2.61	1.57	1.50	2.31
Coarctation of aorta	4.32	5.09	5.37	5.45	5.18	6.46	4.75
Choanal atresia, bilateral	0.96	1.49	1.12	0.87	0.55	0.79	0.46
Cleft palate without cleft lip	7.21	8.77	8.97	10.04	12.47	11.90	9.04
Cleft lip with or without cleft palate	14.41	12.02	13.62	10.67	12.23	12.84	11.29
Oesophageal atresia/stenosis with or without fistula	1.44	2.98	3.61	3.08	3.29	4.18	3.89
Small intestine atresia/stenosis	1.92	3.07	2.64	2.21	3.22	2.92	2.71
Anorectal atresia/stenosis	8.17	4.91	5.29	6.80	5.96	7.01	5.35
Undescended testis (36 weeks of gestation or later)	70.62	64.38	67.46	64.33	57.17	44.44	28.91
Hypospadias	24.98	27.89	30.04	35.96	37.01	35.22	29.97
Epispadias	0.00	0.26	0.48	0.24	0.16	0.16	0.33
Indeterminate sex	0.00	0.18	0.24	0.24	0.16	0.24	0.07
Renal agenesis	3.36	3.86	3.04	4.90	4.39	5.04	4.82
Cystic kidney	3.36	2.63	4.89	7.43	7.53	9.69	8.12
Bladder exstrophy	0.00	0.18	0.40	0.16	0.31	0.24	0.20
Polydactyly, preaxial	8.17	9.91	10.74	10.99	12.47	11.90	9.90
Total Limb reduction defects (include unspecified)	4.80	5.09	5.93	6.24	9.65	9.06	6.86
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	4.32	2.98	2.56	3.64	4.70	3.31	3.04
Omphalocele	2.88	2.11	2.88	3.40	3.37	4.81	3.96
Gastroschisis	0.48	1.58	1.68	2.77	4.08	3.07	4.29
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.00	0.07
Prune belly sequence	0.48	0.70	0.48	0.63	0.16	0.00	0.13
Trisomy 13	0.96	0.61	1.12	1.82	2.04	3.23	2.90
Trisomy 18	0.96	1.75	2.16	3.87	6.04	7.41	7.92
Down syndrome, all ages (include age unknown)	11.05	12.37	15.38	18.49	21.33	26.24	28.25
<20	0.00	4.71	7.86	6.41	11.63	10.53	8.08
20-24	4.90	4.65	8.13	6.30	7.24	6.84	8.29
25-29	8.74	9.02	8.05	8.16	11.40	10.35	11.15
30-34	23.84	11.87	14.19	20.25	16.00	19.92	17.74
35-39	20.94	54.17	39.47	41.87	44.25	54.24	60.60
40-44	0.00	138.20	230.18	167.08	172.15	152.36	204.41
45+	588.24	500.00	434.78	476.19	251.57	469.48	459.18
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 7 years

Australia: WARDA

Time trends 1980-2010 (Birth prevalence rates per 10,000)

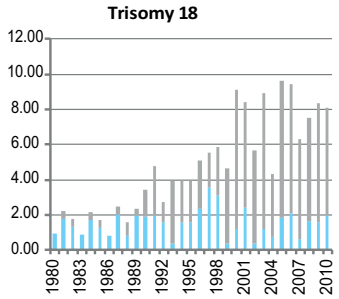


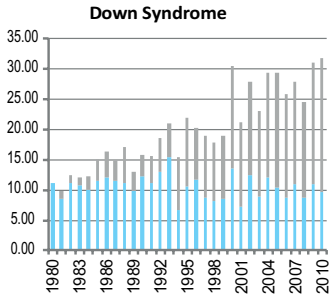
Note: L+S rates, ToP rates

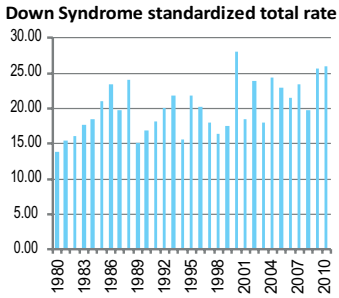
Australia: WARDA

Note: L+S rates, ToP rates

Australia: WARDA







Note: L+S rates, ToP rates

Canada-Alberta: ACASS
Alberta Congenital Anomalies Surveillance System

History:
The programme began in 1963 as a general Registry for Handicapped Children. This was disbanded in 1980 and continued as a surveillance system for live and stillborn infants with congenital anomalies who were born in the province of Alberta.

Size and coverage:
All live and stillbirths in the province are covered which at present comprise about 50,000 births per year. The definition of stillbirth is 20 weeks or more gestation or 500 grams or more birth weight. The vast majority of births occur in hospital (approximately 97%). Since 1997, fetuses with congenital anomalies who were either spontaneously lost before 20 weeks or where there was a termination of pregnancy as a result of prenatal diagnosis have been included.

Legislation and funding:
Although reporting is voluntary, the Health Information Act allows ACASS to receive and others to submit data on infants with congenital anomalies. The system is run by members of the Department of Medical Genetics, Alberta Children's Hospital/University of Calgary, reporting to Alberta Health, Surveillance and Assessment. Funding is from the Alberta Ministry of Health.

Sources of ascertainment:
Reports are obtained from physicians' notices of birth, live birth and stillbirth registrations, death registrations and a special congenital anomalies reporting form (CARF) from hospitals. The latter is based on discharge diagnosis, including readmissions for any reason up to one year of age. Additional sources include cytogenetics laboratories, the provincial metabolic screening programme and specialty clinics such as medical genetics.

Exposure information:
None is routine.

Background information:
Linkage studies are possible with other statistical data from Alberta Health.

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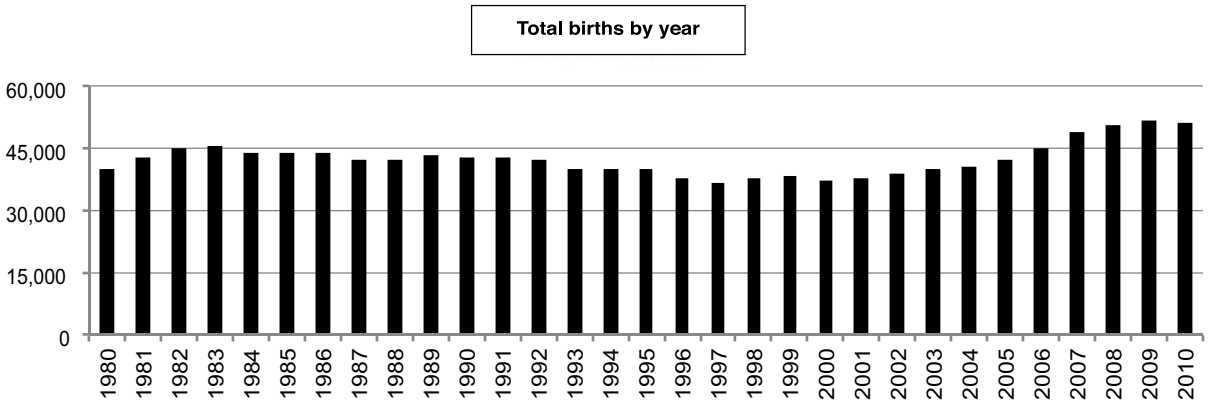
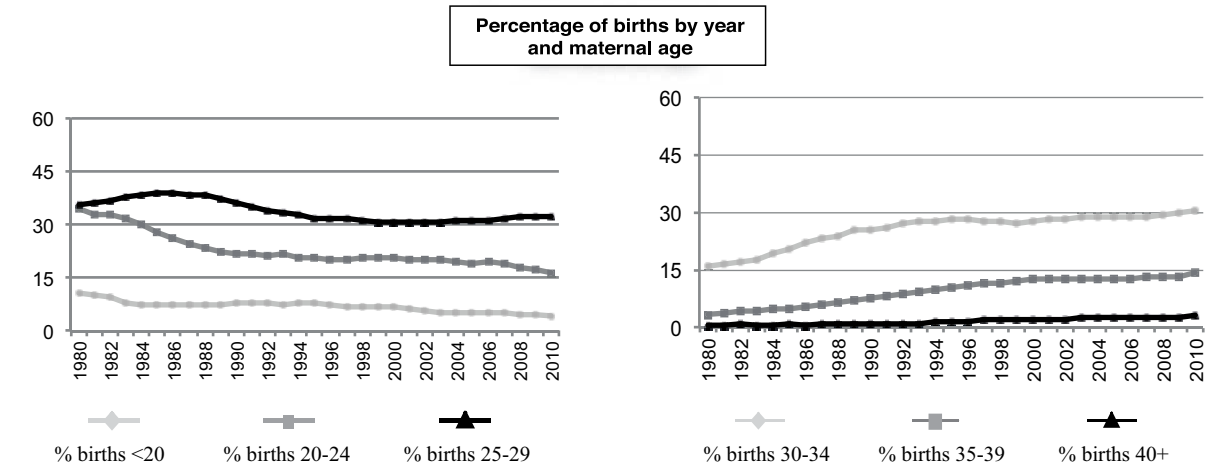
Canada-Alberta: ACASS





Terminations of pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	16	43.2	Cystic kidney	12	11.2
Spina bifida	10	15.9	Limb reduction defects	42	23.1
Encephalocele	2	9.5	Diaphragmatic hernia	4	7.1
Holoprosencephaly	14	37.8	Omphalocele	27	40.3
Hydrocephaly	10	11.5	Gastroschisis	1	1.5
Hypoplastic left heart syndrome	2	4.5	Trisomy 13	23	51.1
Cleft palate without cleft lip	15	13.9	Trisomy 18	45	48.9
Cleft lip with or without cleft palate	14	6.8	Down syndrome	99	30.2
Renal agenesis	4	17.4			

Total ToPs with births defects = 370 (Ratio ToPs/Births: 2.42 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Canada-Alberta: ACASS, 2010

Live births (LB)	50,601
Stillbirths (SB)	362
Total births	50,963
Number of terminations of pregnancy (ToP) for birth defects	140

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	4	2	1.77
Spina bifida	8	11	3	4.32
Encephalocele	5	1	1	1.37
Microcephaly	18	1	0	3.73
Holoprosencephaly	3	0	5	1.57
Hydrocephaly	15	10	2	5.30
Anophthalmos	2	0	0	0.39
Microphthalmos	1	2	0	0.59
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.20
Microtia	13	0	0	2.55
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	13	0	0	2.55
Tetralogy of Fallot	8	2	3	2.55
Hypoplastic left heart syndrome	9	3	1	2.55
Coarctation of aorta	24	1	1	5.10
Choanal atresia, bilateral	7	0	0	1.37
Cleft palate without cleft lip	26	2	6	6.67
Cleft lip with or without cleft palate	62	3	5	13.74
Oesophageal atresia/stenosis with or without fistula	13	0	0	2.55
Small intestine atresia/stenosis	6	2	0	1.57
Anorectal atresia/stenosis	19	0	2	4.12
Undescended testis (36 weeks of gestation or later)	133	0	0	26.10
Hypospadias	125	0	1	24.72
Epispadias	5	0	0	0.98
Indeterminate sex	3	0	1	0.78
Renal agenesis	1	2	2	0.98
Cystic kidney	33	4	5	8.24
Bladder exstrophy	4	0	0	0.78
Polydactyly, preaxial	77	1	10	17.27
Total Limb reduction defects (include unspecified)	24	9	12	8.83
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	17	1	0	3.53
Omphalocele	9	3	13	4.91
Gastroschisis	18	1	0	3.73
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	2	1	0	0.59
Trisomy 13	5	0	5	1.96
Trisomy 18	7	9	17	6.48
Down syndrome, all ages (include age unknown)	68	19	37	24.33
<20	3	0	0	13.82
20-24	2	3	2	8.37
25-29	13	2	4	11.59
30-34	18	5	11	22.10
35-39	17	6	10	46.42
40-44	15	2	10	195.65
45+	0	1	0	140.85
unknown	0	0	0	---

nr = not reported

Canada-Alberta: ACASS, Previous years rates 1980 - 2010

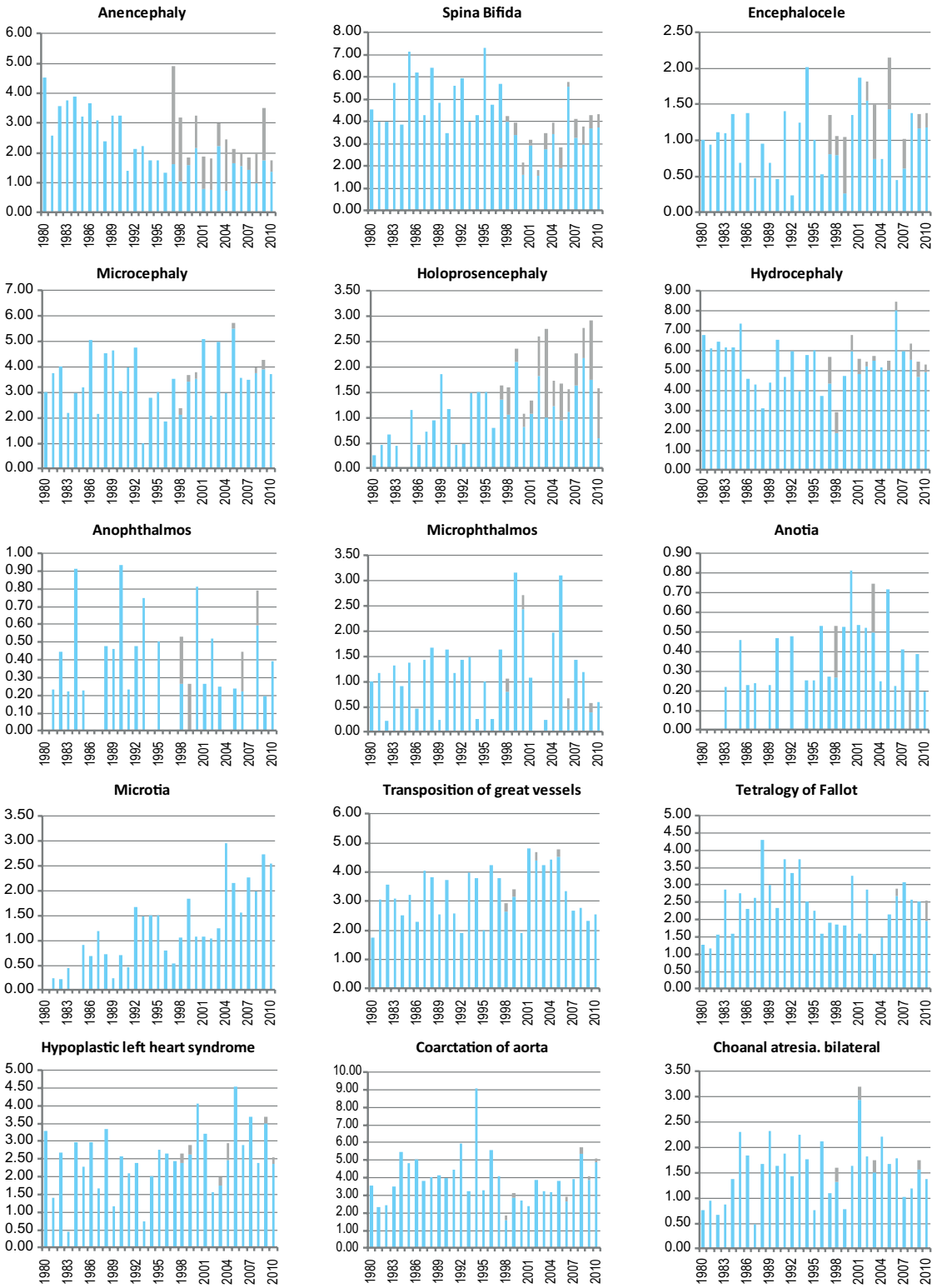
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**39,655**	**220,272**	**213,588**	**204,271**	**187,123**	**198,574**	**246,559**
Anencephaly	4.54	3.40	3.14	1.86	2.89	2.27	2.23
Spina bifida	4.54	4.95	5.06	5.43	4.17	3.07	4.42
Encephalocele	1.01	1.04	0.80	1.17	1.07	1.61	1.14
Microcephaly	3.03	3.22	3.89	3.13	3.05	4.18	3.81
Holoprosencephaly	0.25	0.54	1.03	1.08	1.50	2.01	2.23
Hydrocephaly	6.81	6.45	4.59	5.29	4.76	5.49	6.25
Anophthalmos	0.00	0.41	0.37	0.39	0.32	0.25	0.37
Microphthalmos	1.01	1.00	1.08	1.08	1.76	1.31	0.89
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.00	0.14	0.23	0.20	0.53	0.55	0.28
Microtia	0.00	0.36	0.70	1.32	1.07	1.71	2.23
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	1.77	3.09	3.28	2.84	3.26	4.58	2.72
Tetralogy of Fallot	1.26	2.00	2.90	3.13	2.08	1.81	2.72
Hypoplastic left heart syndrome	3.28	1.95	2.34	2.01	2.94	2.87	3.04
Coarctation of aorta	3.53	3.72	4.21	5.19	3.47	3.32	4.38
Choanal atresia, bilateral	0.76	1.23	1.59	1.62	1.44	2.12	1.42
Cleft palate without cleft lip	6.30	6.22	8.05	7.88	8.50	7.86	6.53
Cleft lip with or without cleft palate	11.10	10.21	12.36	11.80	11.38	12.49	13.51
Oesophageal atresia/stenosis with or without fistula	0.50	2.95	3.23	2.30	2.40	2.22	2.31
Small intestine atresia/stenosis	0.50	0.77	1.22	1.42	1.92	1.36	1.66
Anorectal atresia/stenosis	3.53	3.50	5.34	4.94	5.45	6.45	4.06
Undescended testis (36 weeks of gestation or later)	22.70	27.10	29.45	25.26	23.41	25.68	26.97
Hypospadias	17.65	17.43	26.22	22.08	18.86	20.85	21.82
Epispadias	0.76	0.45	0.23	0.44	0.48	0.81	0.77
Indeterminate sex	0.25	0.36	0.70	1.13	1.39	1.36	1.26
Renal agenesis	2.27	2.41	2.67	1.66	1.39	1.71	1.26
Cystic kidney	0.25	2.81	4.35	4.85	5.83	8.41	6.89
Bladder exstrophy	0.00	0.36	0.23	0.34	0.27	0.45	0.45
Polydactyly, preaxial	13.37	9.40	15.82	14.69	12.08	16.42	18.74
Total Limb reduction defects (include unspecified)	6.56	6.36	9.88	10.18	10.85	12.29	10.87
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	2.77	3.81	2.86	2.40	3.53	3.83	3.53
Omphalocele	1.26	1.86	2.29	1.81	2.30	2.62	3.61
Gastroschisis	1.51	1.41	1.45	1.71	2.57	3.98	4.83
Unspecified Omphalocele/Gastroschisis	0.50	0.59	0.52	0.29	0.00	0.00	0.00
Prune belly sequence	0.50	0.45	0.33	0.10	0.48	0.50	0.20
Trisomy 13	0.50	0.82	0.80	1.37	1.44	1.91	3.12
Trisomy 18	1.26	1.59	1.92	2.35	3.95	4.78	5.56
Down syndrome, all ages (include age unknown)	12.10	8.67	10.16	11.21	15.50	21.35	21.58
<20	nr	nr	6.32	3.15	7.68	10.91	6.77
20-24	nr	nr	5.52	6.68	4.98	6.34	7.70
25-29	nr	nr	6.31	7.83	8.20	11.18	10.15
30-34	nr	nr	12.52	13.88	14.12	16.86	17.56
35-39	nr	nr	34.67	24.83	39.29	54.28	49.93
40-44	nr	nr	101.15	72.63	146.28	184.70	177.92
45+	nr	nr	178.57	389.61	300.00	209.42	397.55
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 7 years

Canada-Alberta: ACASS

Time trends 1980-2010 (Birth prevalence rates per 10,000)

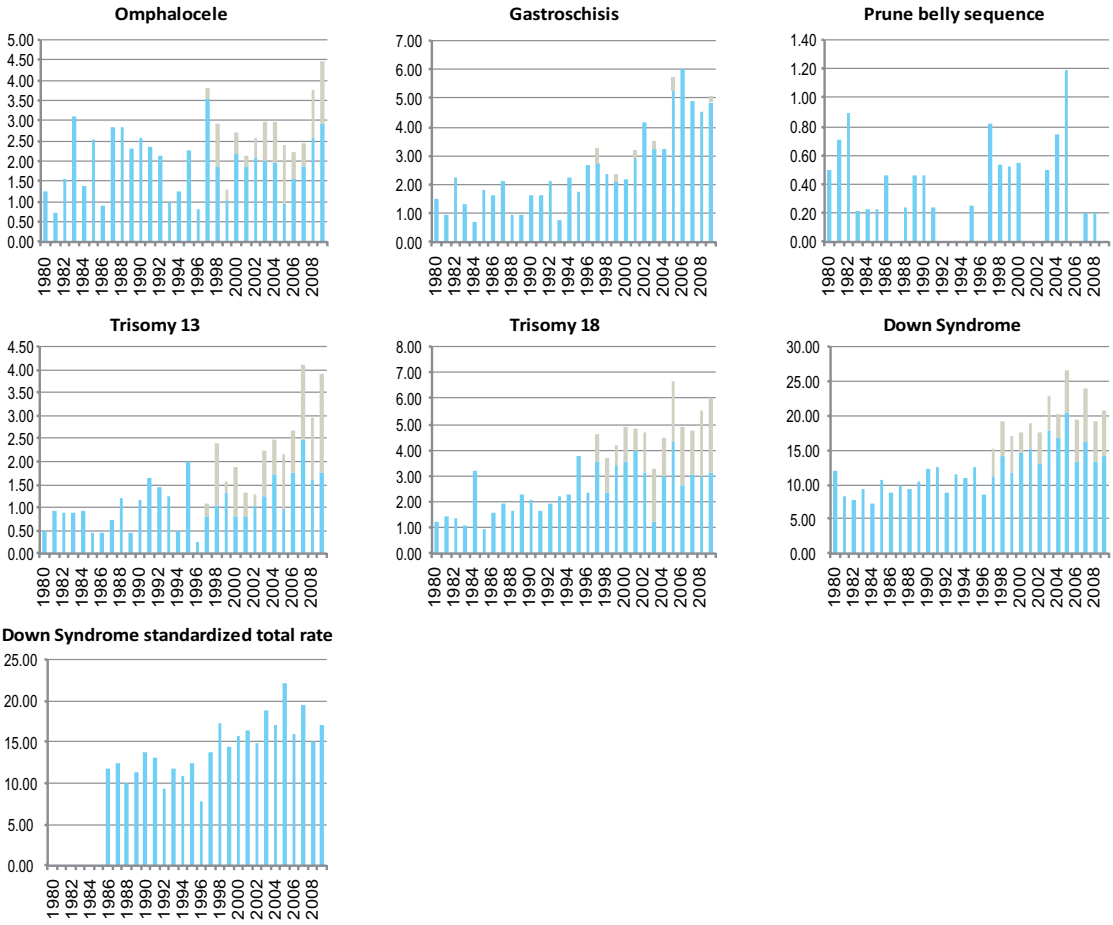


Note: L+S rates, ToP rates

Canada-Alberta: ACASS

Note: L+S rates, ToP rates

Canada-Alberta: ACASS



Note: L+S rates, ToP rates

Canada National: CCASS

Canadian Congenital Anomalies Surveillance System

History:
The Programme was started in 1966. The Programme was a full member until 1987, when it became an associate member. The Programme was discontinued as an associate member of the ICBDSR in the early 1990s, and reinstated its member status in 1996.

Size and coverage:
This system presently monitors about 330,000 births annually, which captures virtually all live births and registered stillbirths (a birth weight of greater or equal to 500 grams, or greater than or equal to 20 weeks in pregnancy) in the 10 provinces and 3 territories of Canada.

Legislation and funding:
Reporting is done by the Public Health Agency of Canada (PHAC) as part of its national surveillance mandate. For congenital anomalies reporting, PHAC uses hospitalization data obtained through the Canadian Institute for Health Information (CIHI). Med-Echo (Système de maintenance et d'exploitation des données pour l'étude de la clientèle hospitalière) for the province of Québec provides their data separately up to 2007.

Sources of ascertainment:
Cases from most provinces and territories are ascertained from hospital admission/separation summary records collected by CIHI and Med-Echo. The Alberta Congenital Anomalies Surveillance System provides its own separate provincial data. All data sources had a one year follow-up period until 2000. Since 2001, all data provided by CIHI only include a 30-day followup period.

Exposure information:
Currently no exposure information is routinely collected.

Background information:
Background information is based on hospital admission/separation summary records from CIHI and Med-Echo. Alberta Congenital Anomalies Surveillance provides its own background information. Interpretation of trends should be done cautiously, since 2001 an increasing percentage of records are being coded using ICD-10 CA and may cause discrepancies from previously used ICD-9 coding. Also, as mentioned previously the variation in the follow-up period is another factor which may alter reporting of trends.

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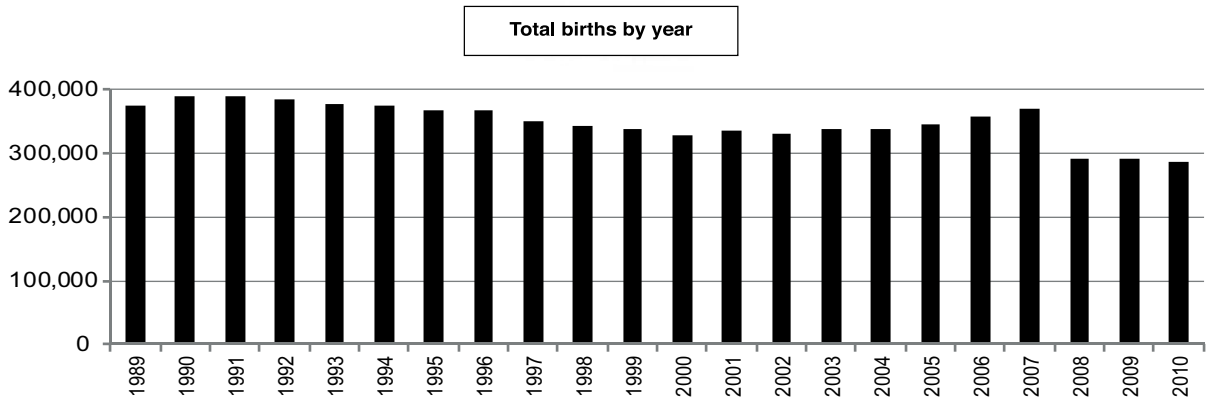
Canada National: CCASS



Canada National: CCASS, 2010

Live births (LB)	285,547
Stillbirths (SB)	2,282
Total births	287,829
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	16	28	nr	1.53
Spina bifida	74	26	nr	3.47
Encephalocele	13	10	nr	0.80
Microcephaly	101	2	nr	3.58
Holoprosencephaly	12	14	nr	0.90
Hydrocephaly	119	26	nr	5.04
Anophthalmos	8	0	nr	0.28
Microphthalmos	20	0	nr	0.69
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	29	0	nr	1.01
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	138	3	nr	4.90
Tetralogy of Fallot	78	6	nr	2.92
Hypoplastic left heart syndrome	61	13	nr	2.57
Coarctation of aorta	114	1	nr	4.00
Choanal atresia, bilateral	72	0	nr	2.50
Cleft palate without cleft lip	182	0	nr	6.32
Cleft lip with or without cleft palate	277	7	nr	9.87
Oesophageal atresia/stenosis with or without fistula	69	0	nr	2.40
Small intestine atresia/stenosis	105	2	nr	3.72
Anorectal atresia/stenosis	116	0	nr	4.03
Undescended testis (36 weeks of gestation or later) (*)	982	2	nr	34.19
Hypospadias	827	0	nr	28.73
Epispadias	19	0	nr	0.66
Indeterminate sex	38	2	nr	1.39
Renal agenesis	139	19	nr	5.49
Cystic kidney	195	10	nr	7.12
Bladder exstrophy	7	0	nr	0.24
Polydactyly, preaxial	368	1	nr	12.82
Total Limb reduction defects (include unspecified)	79	8	nr	3.02
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	88	6	nr	3.27
Omphalocele	49	8	nr	1.98
Gastroschisis	109	9	nr	4.10
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	12	11	nr	0.80
Trisomy 18	42	31	nr	2.54
Down syndrome, all ages (include age unknown)	367	74	nr	15.32
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported
(*) No information on gestational age
Province of Quebec excluded

Canada National: CCASS, Previous years rates 1989 - 2010

Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990*	1991-1995	1996-2000	2001-2005	2006-2010
Total births			**766,679**	**1,895,384**	**1,729,454**	**1,687,704**	**1,599,805**
Anencephaly			2.19	1.81	1.14	1.03	1.38
Spina bifida			7.94	6.58	4.53	3.05	3.63
Encephalocele			1.32	1.37	0.91	0.69	0.83
Microcephaly			6.07	5.08	5.69	5.11	3.90
Holoprosencephaly			nr	nr	nr	nr	0.97
Hydrocephaly			7.40	6.86	6.82	5.20	5.54
Anophthalmos			0.30	0.32	0.25	0.21	0.23
Microphthalmos			1.04	0.98	1.03	0.79	0.79
Unspecified Anophthalmos/Microphthalmos			nr	nr	nr	nr	nr
Anotia			nr	nr	nr	nr	0.05
Microtia			nr	nr	nr	nr	1.12
Unspecified Anotia/Microtia			nr	nr	nr	nr	nr
Transposition of great vessels			4.38	4.76	5.65	4.76	5.59
Tetralogy of Fallot			4.73	4.67	5.22	3.96	3.96
Hypoplastic left heart syndrome			3.14	2.84	2.84	2.75	2.81
Coarctation of aorta			5.40	5.61	5.94	5.02	5.29
Choanal atresia, bilateral			2.06	2.06	2.68	2.76	2.57
Cleft palate without cleft lip			7.07	6.94	7.56	7.21	7.66
Cleft lip with or without cleft palate			11.50	11.14	10.76	9.24	11.01
Oesophageal atresia/stenosis with or without fistula			3.61	3.26	3.52	2.80	2.84
Small intestine atresia/stenosis			3.56	3.45	3.64	3.92	4.48
Anorectal atresia/stenosis			5.73	4.94	4.94	4.25	4.44
Undescended testis (36 weeks of gestation or later)			36.26	33.10	33.36	39.35	41.31
Hypospadias			27.17	26.06	28.15*	nr	32.03
Epispadias			nr	nr	nr	nr	0.76
Indeterminate sex			0.81	0.65	0.67	1.10	1.60
Renal agenesis			5.18	4.83	5.15	5.18	5.98
Cystic kidney			4.38	5.18	6.35	7.12	8.28
Bladder exstrophy			0.44	0.41	0.35	0.39	0.33
Polydactyly, preaxial			12.37	11.57	12.32	14.27	15.76
Total Limb reduction defects (include unspecified)			4.59	4.64	4.04	3.85	3.84
Transverse			nr	nr	nr	nr	nr
Preaxial			nr	nr	nr	nr	nr
Postaxial			nr	nr	nr	nr	nr
Intercalary			nr	nr	nr	nr	nr
Mixed			nr	nr	nr	nr	nr
Unspecified			nr	nr	nr	nr	nr
Diaphragmatic hernia			3.77	3.63	3.77	3.25	3.72
Omphalocele			3.91	6.09	nr	nr	2.51
Gastroschisis			nr	nr	nr	nr	4.81
Unspecified Omphalocele/Gastroschisis			nr	nr	nr	nr	nr
Prune belly sequence			nr	nr	nr	nr	nr
Trisomy 13			1.21	1.16	1.10	1.24	1.23
Trisomy 18			2.15	2.20	2.38	2.39	2.81
Down syndrome, all ages (include age unknown)			13.34	12.98	13.91	14.58	17.14
<20			nr	nr	nr	nr	nr
20-24			nr	nr	nr	nr	nr
25-29			nr	nr	nr	nr	nr
30-34			nr	nr	nr	nr	nr
35-39			nr	nr	nr	nr	nr
40-44			nr	nr	nr	nr	nr
45+			nr	nr	nr	nr	nr
unknown			---	---	---	---	---

nr = not reported
* data include less than 5 years

Canada National: CCASS

Time trends 1989-2010 (Birth prevalence rates per 10,000)

Note: L+S rates

Canada National: CCASS

Note: L+S rates

Chile-Maule: RRMC-SSM

Regional Register Congenital Malformational Maule Health Service

History:
The register started in 2001 defined by order of Director Maule Health Service and assessed for South America.ECLAMC (Latin American Collaborative Study of Congenital Malformations) RRMC-SSM became a member of ICBDSR in 2003.

Size and coverage:
RRMC-SSM is located in a Region in the center of Chile, in Talca Maule Region.
Maule Region is situated between 34º 41' & 36º 33' S and 70º 20' & 72º 44' W. The surface is 30.535 kms2 (4 % of Chile). 930,306 habitants. 37,4% rurality.
Cellulosa producer and agricultural products.
The number of participating are 13 public hospitals from 2001 and since 2004 will included the unique private maternity of the region. There are around 13.500 births annually (2002).
The information about livebirths and stillbirths are collected from 13 maternity hospitals in the region for pediatricians and midwives. Stillbirths of at least 500g birthweight have been included since 2001.

Legislation and funding:
The registry is based on the information of births and notification of congenital malformation ECLAMC from 2001 and funded by the Maule Health Service.

Sources of ascertainment:
Reporting is made by collaborating pediatricians and midwives at the delivery units of participating hospitals.

Exposure information:
Detailed information on various risk factor exposures, maternal and paternal occupation, diseases and other information available.

Background information:
Epidemiological information on all births is available from participating hospitals and statisticals units.

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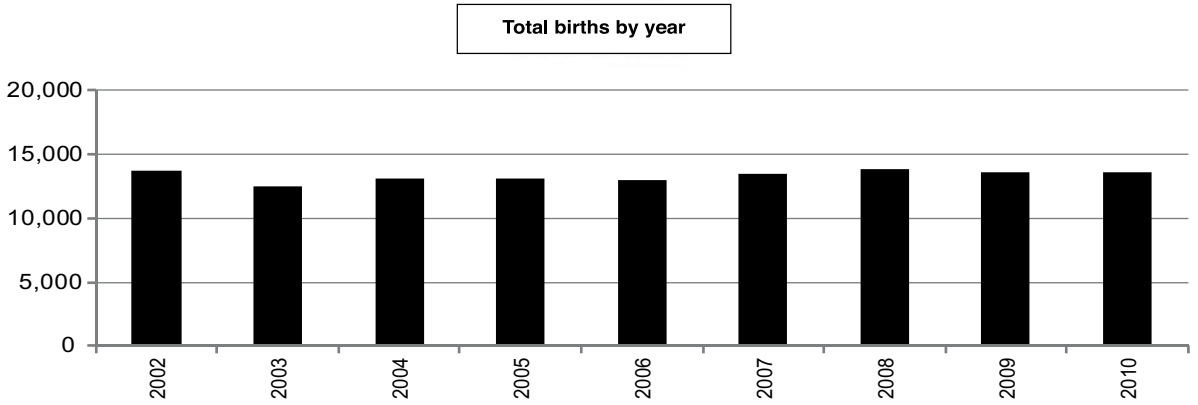
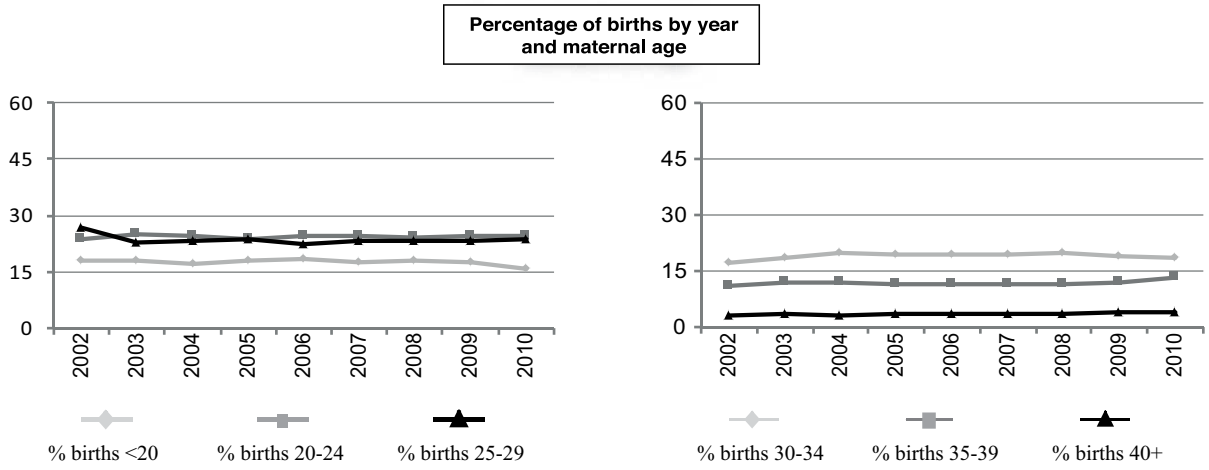
Chile-Maule: RRMC-SSM





Chile-Maule: RRMC-SSM, 2010

Live births (LB)	13,563
Stillbirths (SB)	82
Total births	13,645
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	2		3.66
Spina bifida	2	0		1.47
Encephalocele	1	0		0.73
Microcephaly	1	0		0.73
Holoprosencephaly	1	1		1.47
Hydrocephaly	2	0		1.47
Anophthalmos	0	1		0.73
Microphthalmos	0	0		0.00
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	8	0		5.86
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	1	0		0.73
Tetralogy of Fallot	1	0		0.73
Hypoplastic left heart syndrome	1	0		0.73
Coarctation of aorta	3	0		2.20
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	8	0		5.86
Cleft lip with or without cleft palate	16	1		12.46
Oesophageal atresia/stenosis with or without fistula	1	0		0.73
Small intestine atresia/stenosis	3	0		2.20
Anorectal atresia/stenosis	0	1		0.73
Undescended testis (36 weeks of gestation or later)	9	0		6.60
Hypospadias	7	0		5.13
Epispadias	1	0		0.73
Indeterminate sex	1	0		0.73
Renal agenesis	3	1		2.93
Cystic kidney	1	1		1.47
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	10	3		9.53
Total Limb reduction defects (include unspecified)	4	0		2.93
Transverse	0	0		0.00
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	0	0		0.00
Mixed	0	0		0.00
Unspecified	4	0		2.93
Diaphragmatic hernia	2	0		1.47
Omphalocele	2	0		1.47
Gastroschisis	1	0		0.73
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	2	2		2.93
Trisomy 18	1	0		0.73
Down syndrome, all ages (include age unknown)	16	3		13.92
<20	3	0		13.76
20-24	0	0		0.00
25-29	0	0		0.00
30-34	1	0		3.93
35-39	8	2		55.74
40-44	4	0		77.07
45+	0	1		666.67
unknown	0	0		---

Chile-Maule: RRMC-SSM, Previous years rates 2002 - 2010

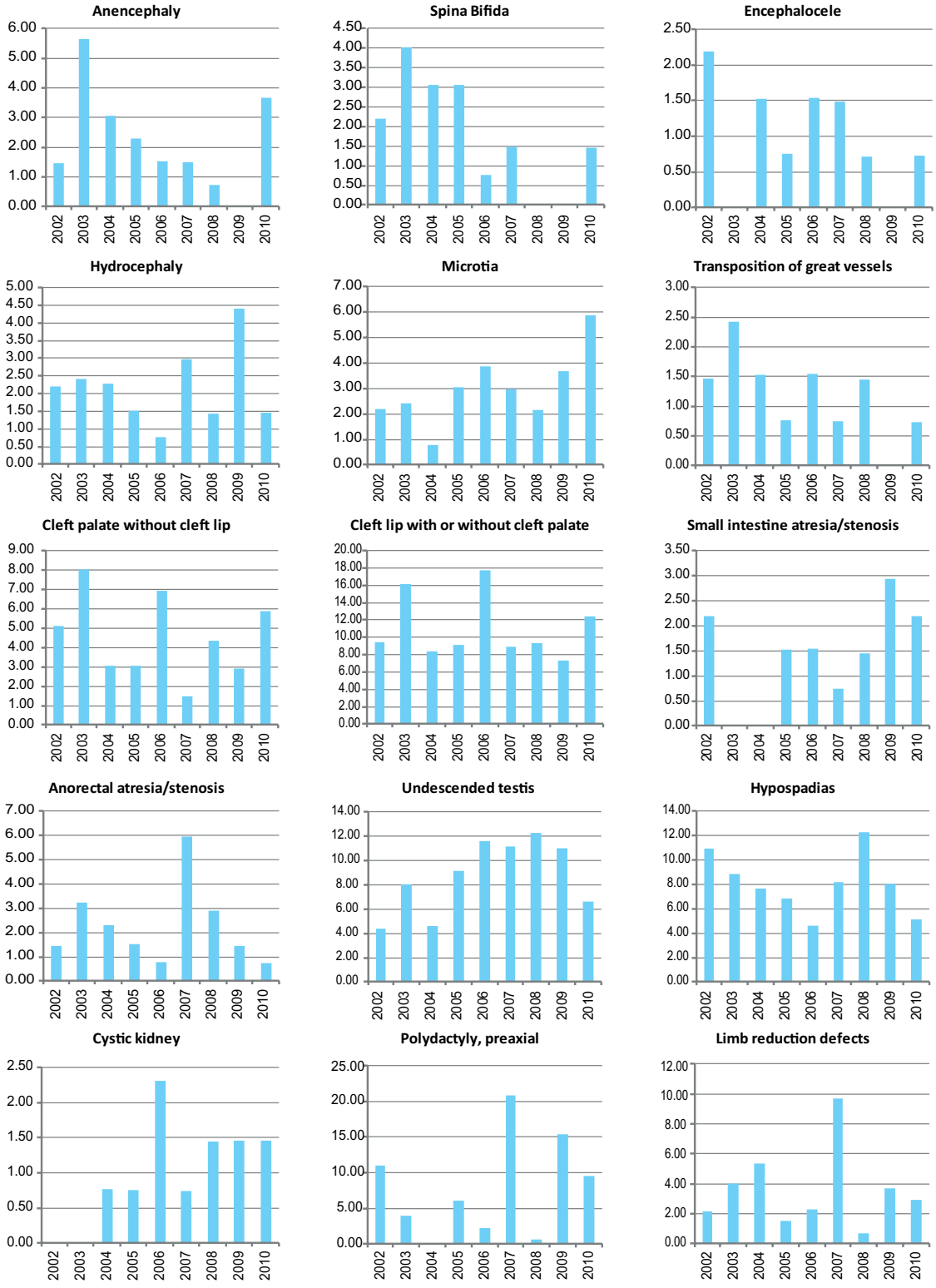
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005*	2006-2010
Total births						**52,358**	**67,542**
Anencephaly						3.06	1.48
Spina bifida						3.06	0.74
Encephalocele						1.15	0.89
Microcephaly						1.72	0.89
Holoprosencephaly						0.38	0.30
Hydrocephaly						2.10	2.22
Anophthalmos						0.19	0.15
Microphthalmos						0.95	0.15
Unspecified Anophthalmos/Microphthalmos						0.00	0.00
Anotia						0.38	0.00
Microtia						2.10	3.70
Unspecified Anotia/Microtia						0.00	0.00
Transposition of great vessels						1.53	0.89
Tetralogy of Fallot						1.34	0.74
Hypoplastic left heart syndrome						0.19	0.59
Coarctation of aorta						0.00	0.74
Choanal atresia, bilateral						0.76	0.00
Cleft palate without cleft lip						4.77	4.29
Cleft lip with or without cleft palate						10.70	11.10
Oesophageal atresia/stenosis with or without fistula						1.15	1.04
Small intestine atresia/stenosis						0.95	1.78
Anorectal atresia/stenosis						2.10	2.37
Undescended testis (36 weeks of gestation or later)						6.49	10.51
Hypospadias						8.59	7.70
Epispadias						0.19	0.15
Indeterminate sex						0.57	0.74
Renal agenesis						0.76	1.78
Cystic kidney						0.38	1.48
Bladder exstrophy						0.19	0.00
Polydactyly, preaxial						5.35	9.77
Total Limb reduction defects (include unspecified)						3.25	3.85
Transverse						1.91	1.63
Preaxial						0.38	0.00
Postaxial						0.00	0.00
Intercalary						0.00	0.15
Mixed						0.00	0.00
Unspecified						0.00	2.07
Diaphragmatic hernia						0.76	1.48
Omphalocele						1.34	1.48
Gastroschisis						1.53	2.07
Unspecified Omphalocele/Gastroschisis						0.00	0.44
Prune belly sequence						0.19	0.30
Trisomy 13						1.53	1.18
Trisomy 18						0.76	1.92
Down syndrome, all ages (include age unknown)						23.30	18.51
<20						6.45	10.18
20-24						5.51	6.07
25-29						7.90	3.84
30-34						17.30	13.04
35-39						70.71	52.26
40-44						207.96	150.38
45+						615.38	170.94
unknown						---	---

* data include less than 5 years

Chile-Maule: RRMC-SSM

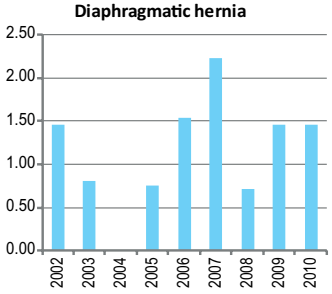
Time trends 2002-2010 (Birth prevalence rates per 10,000)



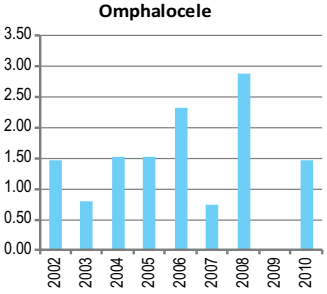
Note: L+S rates

Chile-Maule: RRMC-SSM

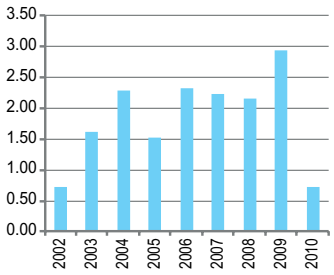
Diaphragmatic hernia



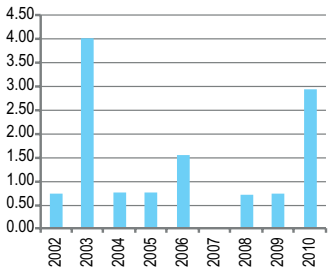
Omphalocele



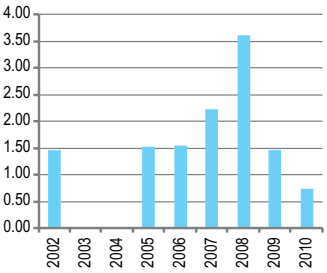
Gastroschisis



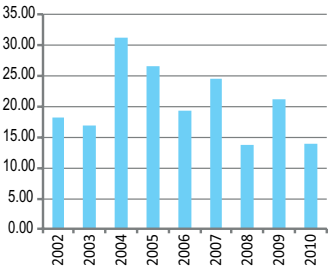
Trisomy 13



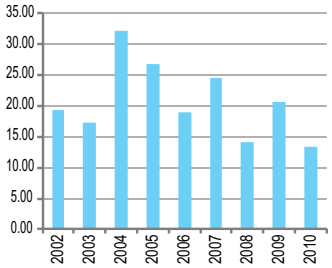
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Colombia-Bogota: BCMSP

Bogota Congenital Malformations Surveillance Program

History:
The Bogota Congenital Malformations Surveillance Program was initiated by the Institute of Human Genetics of the Pontificia Universidad Javeriana in the year 2001 and was developed based on the Latin American Collaborative Study of Congenital Malformations (ECLAMC). In 2006 the health authorities of the city of Bogotá (District Health Secretary of Bogotá) joined the program and since then have become a key ally for its adequate functioning.

Size and Coverage:
The program is hospital based register. In 2001 surveillance began in one hospital of Bogotá D.C. and coverage has been expanded up to a total of 56 hospitals in 2012. In the past year approximately 104,700 births were monitored.

Legislation and funding:
The program is based on the Latin American Collaborative Study of Congenital Malformations, ECLAMC, and is financed by the health authorities of the city of Bogota (District Health Secretary of Bogotá) together with the Pontificia Universidad Javeriana. In 2007 the Ministry of Social Protection issued a decree which enforced the implementation of birth defects surveillance systems.

Sources of ascertainment:
There are two modalities for surveillance: monitor and case-control. The first one depends on the staff of each hospital (nurses, gynecologists, neonatologists), and the latter is held by physicians who are previously trained to actively search for congenital anomalies through a systematic physical exam. Both modalities include a format that obliges health care providers to realize a textual and thorough description of the anomalies according to the ECLAMC manual.

Exposure Information:
The format that is filled out by physicians that participate in the case-control modality includes many variables such as immunizations, acute diseases during pregnancy, chronic diseases, physical factors (x-rays, surgery, radiotherapy etc.), drugs, smoking, recreational drugs, alcohol, level of education of parents and place where they lived during the periconceptional period.

Background information:
Epidemiological information may be accessed at www.anomaliascongenitas.org

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Colombia-Bogota: BCMSP, 2010

Live births (LB)	39,418
Stillbirths (SB)	157
Total births	39,575
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	nr	0.51
Spina bifida	11	0	nr	2.78
Encephalocele	0	0	nr	0.00
Microcephaly	1	0	nr	0.25
Holoprosencephaly	0	0	nr	0.00
Hydrocephaly	8	0	nr	2.02
Anophthalmos	0	0	nr	0.00
Microphthalmos	1	0	nr	0.25
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	27	1	nr	7.08
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	1	0	nr	0.25
Tetralogy of Fallot	0	0	nr	0.00
Hypoplastic left heart syndrome	6	0	nr	1.52
Coarctation of aorta	1	0	nr	0.25
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	7	0	nr	1.77
Cleft lip with or without cleft palate	29	0	nr	7.33
Oesophageal atresia/stenosis with or without fistula	7	1	nr	2.02
Small intestine atresia/stenosis	1	0	nr	0.25
Anorectal atresia/stenosis	7	0	nr	1.77
Undescended testis (36 weeks of gestation or later)	3	0	nr	0.76
Hypospadias	10	0	nr	2.53
Epispadias	0	0	nr	0.00
Indeterminate sex	3	0	nr	0.76
Renal agenesis	3	0	nr	0.76
Cystic kidney	6	1	nr	1.77
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	7	0	nr	1.77
Total Limb reduction defects (include unspecified)	14	2	nr	4.04
Transverse	4	2	nr	1.52
Preaxial	0	0	nr	0.00
Postaxial	5	0	nr	1.26
Intercalary	0	0	nr	0.00
Mixed	4	0	nr	1.01
Unspecified	1	2	nr	0.76
Diaphragmatic hernia	3	0	nr	0.76
Omphalocele	10	2	nr	3.03
Gastroschisis	5	0	nr	1.26
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	1	0	nr	0.25
Trisomy 13	1	0	nr	0.25
Trisomy 18	2	0	nr	0.51
Down syndrome, all ages (include age unknown)	40	0	nr	10.11
<20	5	0	nr	8.61
20-24	0	0	nr	0.00
25-29	8	0	nr	7.96
30-34	7	0	nr	9.32
5-39	7	0	nr	18.62
40-44	12	0	nr	117.88
45+	1	0	nr	100.00
unknown	0	0	nr	---

nr = not reported

Costa Rica: CREC
Costa Rican Birth Defects Register Centre

History:
The registry was created in 1986, based in a government decret by which birth defects became subject of obligatory notification.
The program became an ICBDSR member in September 2003.

Size and coverage:
The program is population based. Includes all births from the National Security System (CCSS) which covers about 98% of all births occurred in the country, and births of private hospitals.
There are approximately 75000 annual births in Costa Rica.

Legislation and funding:
The Registry is financed by the government as a program of the Costa Rican Institute of Research and Training in Nutrition and Health (INCIENSA), Institute that depends from the Ministry of Health.

Sources of ascertainment:
Until 2008 reporting was made only by neonatologists, pediatricians and general physicians before newborns discharge from maternity services, with biostatistics personal collaboration. In 2009 the age of obligatory notification was extended to children under one year of age

Exposure information:
In 2009 began rubella vaccine exposure information collect in order to support the performance of Congenital Rubella Syndrome surveillance

Background information:
Linkage studies are possible with other statistical data from the National Statistics Center and the National Security System Statistical Center

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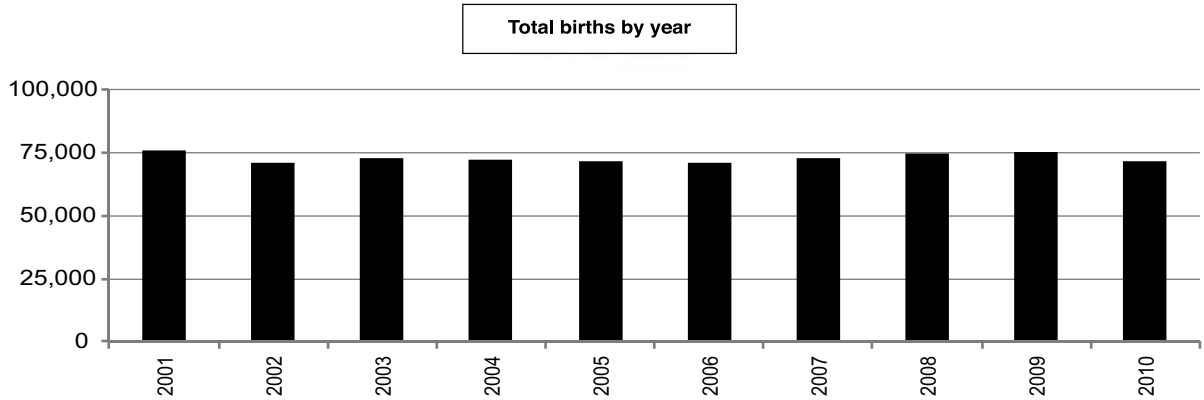
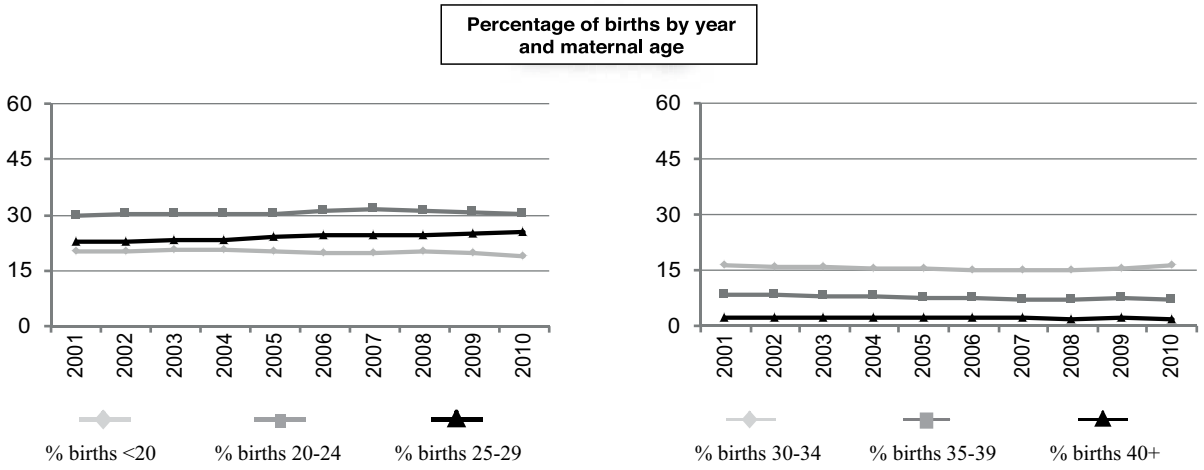
Costa Rica: CREC





Costa Rica: CREC, 2010

Live births (LB)	70,922
Stillbirths (SB)	443
Total births	71,365
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	0		0.42
Spina bifida	14	1		2.10
Encephalocele	2	0		0.28
Microcephaly	37	0		5.18
Holoprosencephaly	0	0		0.00
Hydrocephaly	10	0		1.40
Anophthalmos	1	0		0.14
Microphthalmos	2	0		0.28
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	11	1		1.68
Microtia	16	0		2.24
Unspecified Anotia/Microtia	3	0		0.42
Transposition of great vessels	7	0		0.98
Tetralogy of Fallot	4	0		0.56
Hypoplastic left heart syndrome	8	0		1.12
Coarctation of aorta	3	1		0.56
Choanal atresia, bilateral	4	0		0.56
Cleft palate without cleft lip	17	2		2.66
Cleft lip with or without cleft palate	56	3		8.27
Oesophageal atresia/stenosis with or without fistula	15	1		2.24
Small intestine atresia/stenosis	3	1		0.56
Anorectal atresia/stenosis	18	1		2.66
Undescended testis (36 weeks of gestation or later)	78	0		10.93
Hypospadias	47	0		6.59
Epispadias	0	0		0.00
Indeterminate sex	4	0		0.56
Renal agenesis	6	0		0.84
Cystic kidney	13	0		1.82
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	91	1		12.89
Total Limb reduction defects (include unspecified)	37	0		5.18
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	nr	nr		nr
Diaphragmatic hernia	13	0		1.82
Omphalocele	6	0		0.84
Gastroschisis	18	1		2.66
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	1	0		0.14
Trisomy 13	3	0		0.42
Trisomy 18	6	0		0.84
Down syndrome, all ages (include age unknown)	76	nr		10.65
<20	7	nr		5.28
20-24	6	nr		2.81
25-29	11	nr		6.11
30-34	15	nr		12.88
35-39	16	nr		31.38
40-44	17	nr		134.39
45+	2	nr		210.53
unknown	2	nr		---

nr = not reported

Costa Rica: CREC, Previous years rates 2001 - 2010

Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births						**363,868**	**366,078**
Anencephaly						1.37	1.07
Spina bifida						3.46	2.73
Encephalocele						0.52	0.74
Microcephaly						1.24	2.60
Holoprosencephaly						0.30	0.55
Hydrocephaly						2.12	2.81
Anophthalmos						0.16	0.27
Microphthalmos						0.41	0.49
Unspecified Anophthalmos/Microphthalmos						0.00	0.00
Anotia						0.19	1.12
Microtia						2.25	2.16
Unspecified Anotia/Microtia						0.00	0.14
Transposition of great vessels						0.08	0.71
Tetralogy of Fallot						0.88	0.68
Hypoplastic left heart syndrome						0.33	0.71
Coarctation of aorta						0.33	0.55
Choanal atresia, bilateral						0.27	0.30
Cleft palate without cleft lip						2.39	2.84
Cleft lip with or without cleft palate						6.90	7.24
Oesophageal atresia/stenosis with or without fistula						1.48	1.69
Small intestine atresia/stenosis						0.63	0.46
Anorectal atresia/stenosis						2.72	2.65
Undescended testis (36 weeks of gestation or later)						9.70	10.95
Hypospadias						5.85	7.10
Epispadias						0.05	0.08
Indeterminate sex						1.59	1.45
Renal agenesis						0.69	0.85
Cystic kidney						0.33	1.34
Bladder exstrophy						0.05	0.03
Polydactyly, preaxial						7.39	11.61
Total Limb reduction defects (include unspecified)						4.92	4.53
Transverse						nr	nr
Preaxial						nr	nr
Postaxial						nr	nr
Intercalary						nr	nr
Mixed						nr	nr
Unspecified						nr	nr
Diaphragmatic hernia						1.76	1.39
Omphalocele						0.63	1.23
Gastroschisis						1.46	2.32
Unspecified Omphalocele/Gastroschisis						0.16	0.00
Prune belly sequence						0.30	0.33
Trisomy 13						1.26	0.38
Trisomy 18						1.07	0.85
Down syndrome, all ages (include age unknown)						8.38	9.21
<20						5.42	4.47
20-24						4.67	3.92
25-29						4.50	3.99
30-34						5.58	8.40
35-39						27.37	30.26
40-44						69.67	105.71
45+						94.52	252.29
unknown						---	---

nr = not reported
* data include less than 5 years

Costa Rica: CREC

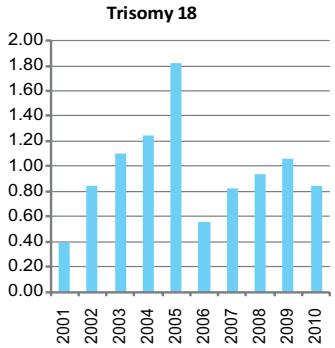
Time trends 2001-2009 (Birth prevalence rates per 10,000)

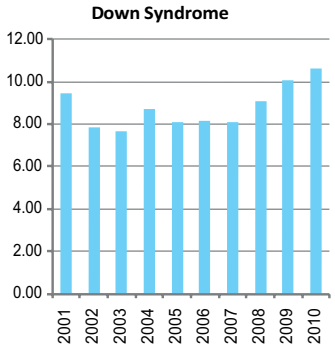
Note: L+S rates

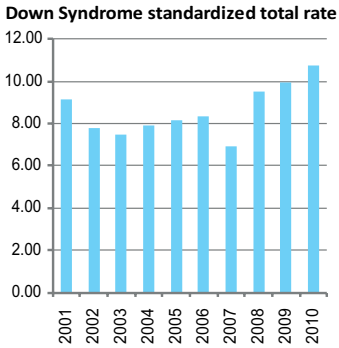
Costa Rica: CREC

Note: L+S rates

Costa Rica: CREC







Note: L+S rates

Cuba: RECUMAC
Cuban Register of Congenital Malformation

History:
The program started in 1985 and has grown in size and coverage. The registry became a member of ICBDSR in 2003.

Size and coverage:
Reports are obtained from hospitals distributed all over Cuba. The number of partecipating hospitals has grown in 1986 to 60 at the present time. The annual number of birth is approximately 121,000 representing almost 96% of all births.

Legislation and funding:
RIt is a research programme with voluntary participation of hospitals. The registry is associated with the National Centre of Medical Genetics, and is financed by Health Public Ministry of Cuba.

Sources of ascertainment:
Reports are obtained from delivery units paediatric departments of the participating hospitals. Mothers are also interviewed directly to gather information and fill in the RECUMAC standard protocols.

Exposure information:
The mother of each reported infant and the mother of a control infant, the next non malformed infant born at the hospital with the same sex as the proband are interviewed on various exposures, including drug usage and parental occupation.

Background information:
Total number of birth by sex and number of twin pairs in each participating hospital are known. Other background information is obtained partly from summarizing tables of births in each participating hospital, partly from the control material.

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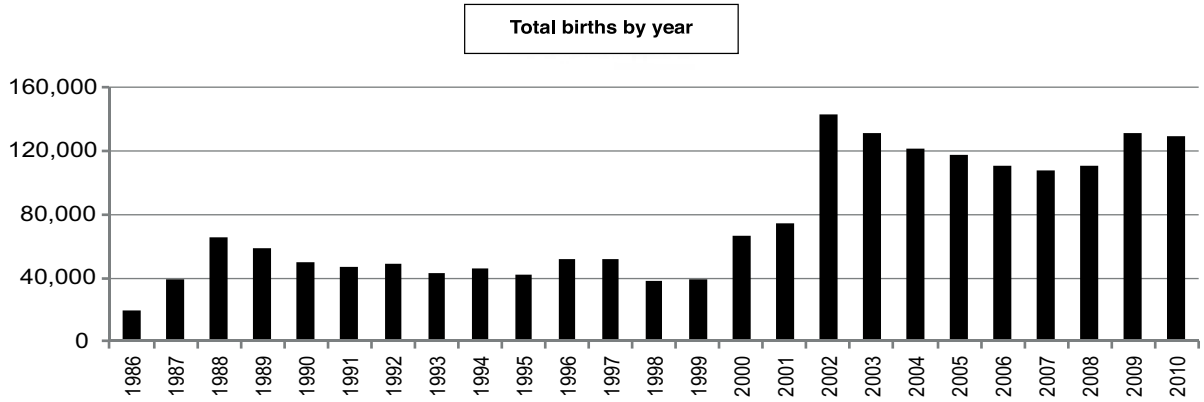
Cuba: RECUMAC



Terminations of pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	147	99.3	Cystic kidney	136	83.4
Spina bifida	123	81.5	Limb reduction defects	23	32.9
Encephalocele	47	88.7	Diaphragmatic hernia	78	72.9
Holoprosencephaly	42	89.4	Omphalocele	94	93.1
Hydrocephaly	234	83.3	Gastroschisis	223	95.3
Hypoplastic left heart syndrome	65	85.5	Trisomy 13	23	79.3
Cleft palate without cleft lip	8	9.4	Trisomy 18	55	78.6
Cleft lip with or without cleft palate	47	27.0	Down syndrome	226	49.2
Renal agenesis	47	78.3			

Total ToPs with births defects = 3,806 (Ratio ToPs/Births: 10.26 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Cuba: RECUMAC, 2010

Live births (LB)	127,746
Stillbirths (SB)	1,393
Total births	129,139
Number of terminations of pregnancy (ToP) for birth defects	1,170

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	58	4.49
Spina bifida	8	0	33	3.17
Encephalocele	1	0	8	0.70
Microcephaly	1	0	3	0.31
Holoprosencephaly	0	2	11	1.01
Hydrocephaly	18	0	69	6.74
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.08
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.23
Microtia	12	0	0	0.93
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	19	1	17	2.87
Tetralogy of Fallot	9	1	17	2.09
Hypoplastic left heart syndrome	3	2	14	1.47
Coarctation of aorta	7	1	1	0.70
Choanal atresia, bilateral	2	0	0	0.15
Cleft palate without cleft lip	35	0	0	2.71
Cleft lip with or without cleft palate	51	0	13	4.96
Oesophageal atresia/stenosis with or without fistula	14	1	10	1.94
Small intestine atresia/stenosis	10	0	19	2.25
Anorectal atresia/stenosis	18	0	3	1.63
Undescended testis (36 weeks of gestation or later)	31	0	0	2.40
Hypospadias	112	0	0	8.67
Epispadias	4	0	0	0.31
Indeterminate sex	8	0	0	0.62
Renal agenesis	5	0	10	1.16
Cystic kidney	17	0	44	4.72
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	6	0	0	0.46
Total Limb reduction defects (include unspecified)	15	0	14	2.25
Transverse	3	0	1	0.31
Preaxial	0	0	0	0.00
Postaxial	1	0	0	0.08
Intercalary	3	0	2	0.39
Mixed	3	0	4	0.54
Unspecified	1	0	7	0.62
Diaphragmatic hernia	11	0	18	2.25
Omphalocele	5	1	31	2.87
Gastroschisis	4	0	64	5.27
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	6	0.46
Trisomy 18	4	0	14	1.39
Down syndrome, all ages (include age unknown)	69	0	73	11.00
<20	7	0	1	4.06
20-24	10	0	3	3.05
25-29	10	0	3	4.06
30-34	12	0	5	8.93
35-39	20	0	35	46.62
40-44	6	0	22	119.00
45+	1	1	0	143.88
unknown	3	0	4	---

Cuba: RECUMAC, Previous years rates 1985 - 2010

Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985*	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**8,552**	**232,717**	**227,273**	**247,335**	**588,391**	**589,617**	
Anencephaly	2.34	0.64	0.57	0.08	3.94	4.24	
Spina bifida	15.20	4.13	2.77	2.18	4.13	4.46	
Encephalocele	0.00	0.52	0.18	0.12	0.66	1.71	
Microcephaly	1.17	0.56	0.35	0.32	0.51	0.41	
Holoprosencephaly	1.17	0.17	0.04	0.08	0.27	0.95	
Hydrocephaly	9.35	3.14	2.20	1.46	6.68	8.70	
Anophthalmos	0.00	0.04	0.04	0.00	0.15	0.03	
Microphthalmos	0.00	0.09	0.00	0.12	0.19	0.15	
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.03	0.03	
Anotia	0.00	0.00	0.00	0.04	0.12	0.17	
Microtia	3.51	0.69	0.62	0.81	0.56	0.61	
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.07	0.00	
Transposition of great vessels	0.00	0.39	0.48	1.01	1.87	1.61	
Tetralogy of Fallot	0.00	0.21	0.31	0.57	1.73	1.85	
Hypoplastic left heart syndrome	1.17	0.64	0.88	0.49	0.93	2.12	
Coarctation of aorta	0.00	0.09	0.04	0.12	0.54	0.39	
Choanal atresia, bilateral	0.00	0.21	0.00	0.16	0.19	0.08	
Cleft palate without cleft lip	1.17	1.33	1.41	1.58	1.72	1.93	
Cleft lip with or without cleft palate	4.68	4.55	5.94	5.98	4.83	4.82	
Oesophageal atresia/stenosis with or without fistula	2.34	1.16	1.41	2.39	2.35	2.49	
Small intestine atresia/stenosis	4.68	0.73	0.66	0.81	1.44	2.65	
Anorectal atresia/stenosis	7.02	1.03	1.67	0.85	1.29	1.27	
Undescended testis (36 weeks of gestation or later)	0.00	4.51	4.18	2.43	2.91	2.31	
Hypospadias	17.54	14.87	12.45	10.67	8.00	9.01	
Epispadias	0.00	0.26	0.22	0.12	0.15	0.25	
Indeterminate sex	0.00	0.21	0.18	0.28	0.39	0.42	
Renal agenesis	1.17	0.56	0.22	0.28	0.76	1.34	
Cystic kidney	3.51	1.12	0.92	0.61	2.18	4.09	
Bladder exstrophy	2.34	0.13	0.13	0.24	0.10	0.03	
Polydactyly, preaxial	2.34	0.04	0.22	0.49	0.80	0.76	
Total Limb reduction defects (include unspecified)	7.02	2.45	2.90	2.39	2.24	2.15	
Transverse	2.34	1.07	0.84	0.69	0.56	0.70	
Preaxial	0.00	0.00	0.00	0.00	0.03	0.03	
Postaxial	0.00	0.00	0.00	0.00	0.00	0.05	
Intercalary	0.00	0.00	0.00	0.00	0.10	0.22	
Mixed	0.00	0.00	0.00	0.00	0.22	0.47	
Unspecified	0.00	0.21	0.75	1.05	1.09	0.63	
Diaphragmatic hernia	1.17	1.42	1.45	1.62	1.70	2.61	
Omphalocele	4.68	0.64	0.57	0.36	1.75	2.32	
Gastroschisis	0.00	0.39	0.35	0.44	2.58	6.46	
Unspecified Omphalocele/Gastroschisis	0.00	0.13	0.00	0.00	0.25	0.02	
Prune belly sequence	0.00	0.09	0.13	0.00	0.03	0.05	
Trisomy 13	1.17	0.47	0.44	0.57	0.83	1.14	
Trisomy 18	0.00	0.13	0.35	0.36	0.71	1.88	
Down syndrome, all ages (include age unknown)	12.86	7.52	8.01	7.28	9.82	12.52	
<20	nr	nr	nr	nr	nr	4.01*	
20-24	nr	nr	nr	nr	nr	3.74*	
25-29	nr	nr	nr	nr	nr	4.10*	
30-34	nr	nr	nr	nr	nr	9.40*	
35-39	nr	nr	nr	nr	nr	48.14*	
40-44	nr	nr	nr	nr	nr	132.49*	
45+	nr	nr	nr	nr	nr	140.35*	
unknown	---	---	---	---	---	---	

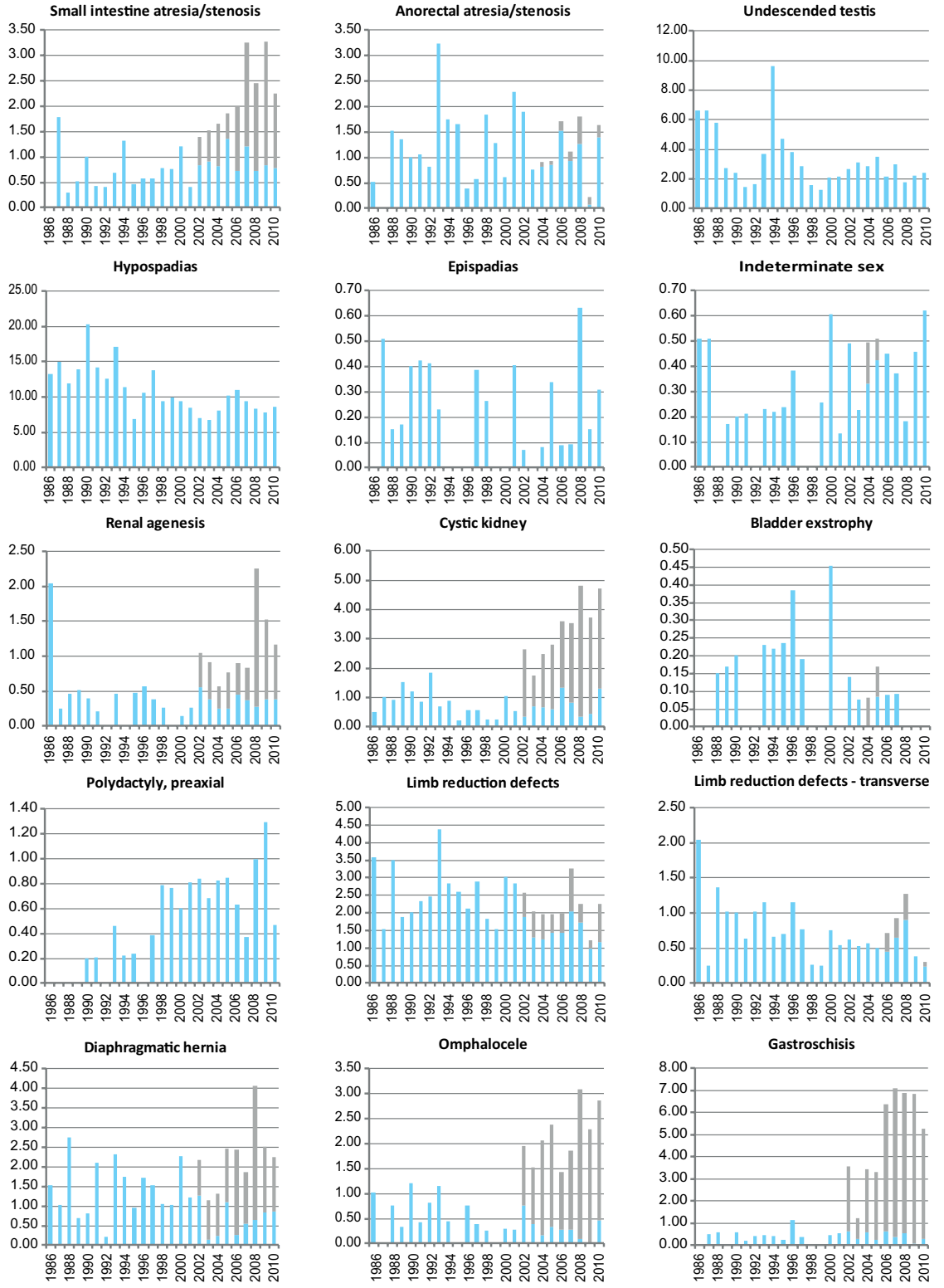
nr = not reported
* data include less than 5 years

Cuba: RECUMAC

Time trends 1986-2010 (Birth prevalence rates per 10,000)

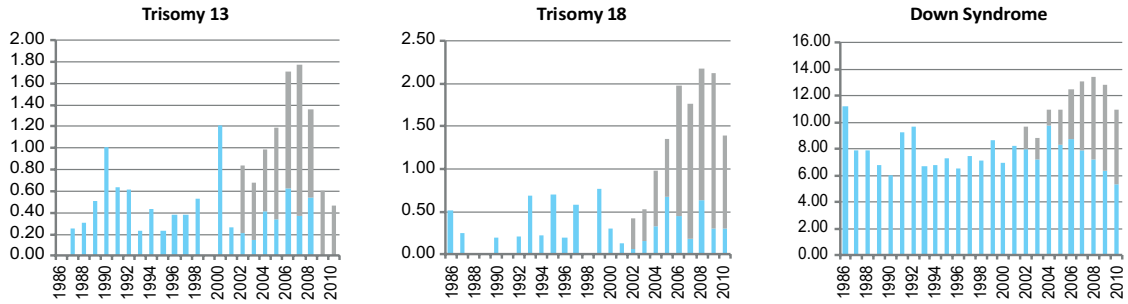
Note: L+S rates, ToP rates

Cuba: RECUMAC



Note: L+S rates, ToP rates

Cuba: RECUMAC



Note: L+S rates, ToP rates

Czech Republic

National Registry of Congenital Anomalies of the Czech Republic

History:
A registration of congenital malformation began in 1961 and regular monitoring started in 1964. The programme was a founding member of the Clearinghouse and is a full member.

Size and coverage:
All births in the Czech Republic (Bohemia, Moravia and Silesia regions) are covered, at present comprising approximately 110,000 annual births. Stillbirths weighting at least 1,000g are included. The information about prenatally diagnosed cases is available from 1994.

Legislation and funding:
Reporting is compulsory. The registration is financed and run by the government in the Institute of Health Information and Statistics of the Czech Republic. Analysis of data is supported by Grant projects (currently none available).

Sources of ascertainment:
Reports are obtained from delivery units, neonatal, paediatric, child surgery, pathology departments and cytogenetic laboratories. Reporting to the central registry occurs via Regional Department of Institute of Health Information and Statistics.

Exposure information:
Some exposure information is available on malformed infants, at present none on controls.

Background information:
Information's on all births are available in the Institute of Health Information and Statistics of the Czech Republic.

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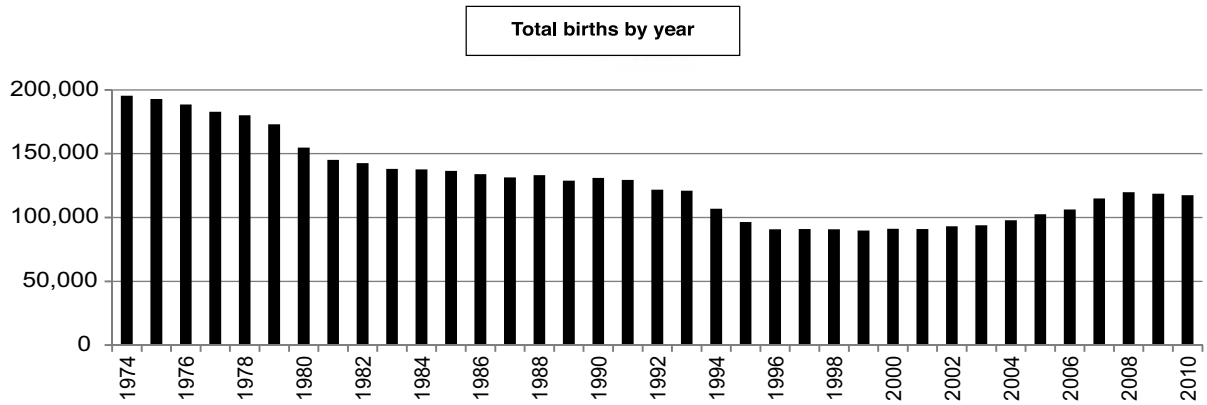
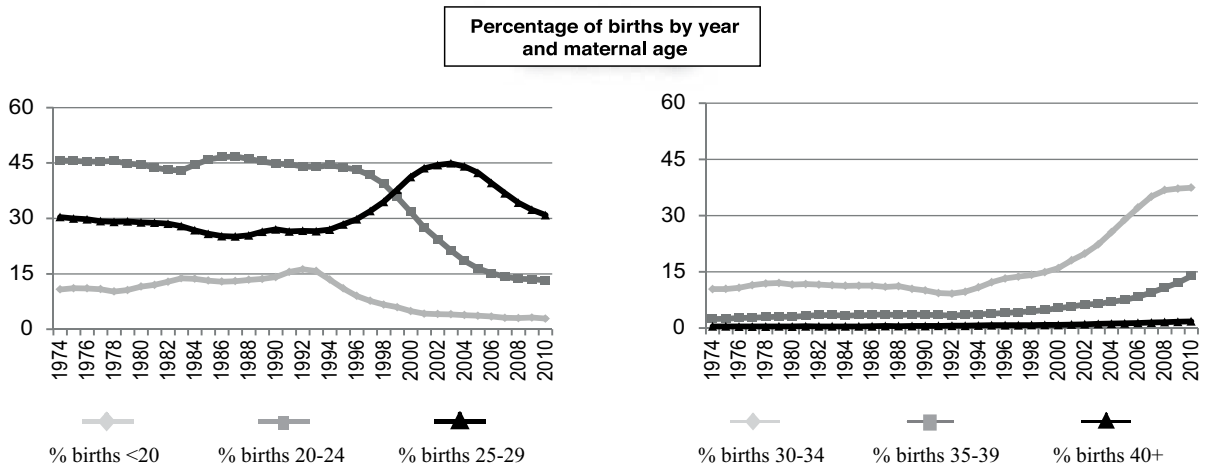
Czech Republic





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	85	97.7	Cystic kidney	39	15.1
Spina bifida	91	70.0	Limb reduction defects	49	20.8
Encephalocele	36	78.3	Diaphragmatic hernia	31	27.7
Holoprosencephaly	21	67.7	Omphalocele	75	64.1
Hydrocephaly	107	60.5	Gastroschisis	78	65.0
Hypoplastic left heart syndrome	112	76.2	Trisomy 13	59	88.1
Cleft palate without cleft lip	0	0.0	Trisomy 18	184	93.9
Cleft lip with or without cleft palate	72	16.2	Down syndrome	656	82.6
Renal agenesis	53	17.0			

Total ToPs with births defects = 2,712 (Ratio ToPs/Births: 7.62 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Czech Republic, 2010

Live births (LB)	117,153
Stillbirths (SB)	293
Total births	117,446
Number of terminations of pregnancy (ToP) for birth defects	925

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	32	2.72
Spina bifida	12	0	23	2.98
Encephalocele	2	1	8	0.94
Microcephaly	17	0	0	1.45
Holoprosencephaly	2	1	6	0.77
Hydrocephaly	26	1	40	5.70
Anophthalmos	1	0	nr	0.09
Microphthalmos	7	0	nr	0.60
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	2	0	nr	0.17
Microtia	5	0	nr	0.43
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	40	0	18	4.94
Tetralogy of Fallot	35	0	15	4.26
Hypoplastic left heart syndrome	11	0	70	6.90
Coarctation of aorta	54	0	8	5.28
Choanal atresia, bilateral	22	0	0	1.87
Cleft palate without cleft lip	86	0	0	7.32
Cleft lip with or without cleft palate	113	0	17	11.07
Oesophageal atresia/stenosis with or without fistula	34	0	1	2.98
Small intestine atresia/stenosis	34	0	4	3.24
Anorectal atresia/stenosis	31	1	1	2.81
Undescended testis (36 weeks of gestation or later)	418	0	nr	35.59
Hypospadias	384	0	1	32.78
Epispadias	2	0	0	0.17
Indeterminate sex	3	0	0	0.26
Renal agenesis	91	0	12	8.77
Cystic kidney	71	0	5	6.47
Bladder exstrophy	2	0	0	0.17
Polydactyly, preaxial	157	0	0	13.37
Total Limb reduction defects (include unspecified)	49	0	12	5.19
Transverse	20	0	nr	1.70
Preaxial	1	0	nr	0.09
Postaxial	0	0	nr	0.00
Intercalary	0	0	nr	0.00
Mixed	28	0	nr	2.38
Unspecified	0	0	nr	0.00
Diaphragmatic hernia	34	0	13	4.00
Omphalocele	17	1	29	4.00
Gastroschisis	17	0	29	3.92
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	4	0.34
Trisomy 13	1	0	20	1.79
Trisomy 18	9	1	61	6.05
Down syndrome, all ages (include age unknown)	45	0	231	23.50
<20	3	0	2	14.85
20-24	2	0	3	3.23
25-29	4	0	24	7.72
30-34	15	0	70	19.34
35-39	10	0	80	55.38
40-44	10	0	5	74.29
45+	1	0	7	909.09
unknown	0	0	0	---

nr = not reported

Czech Republic, Previous years rates 1974 - 2010

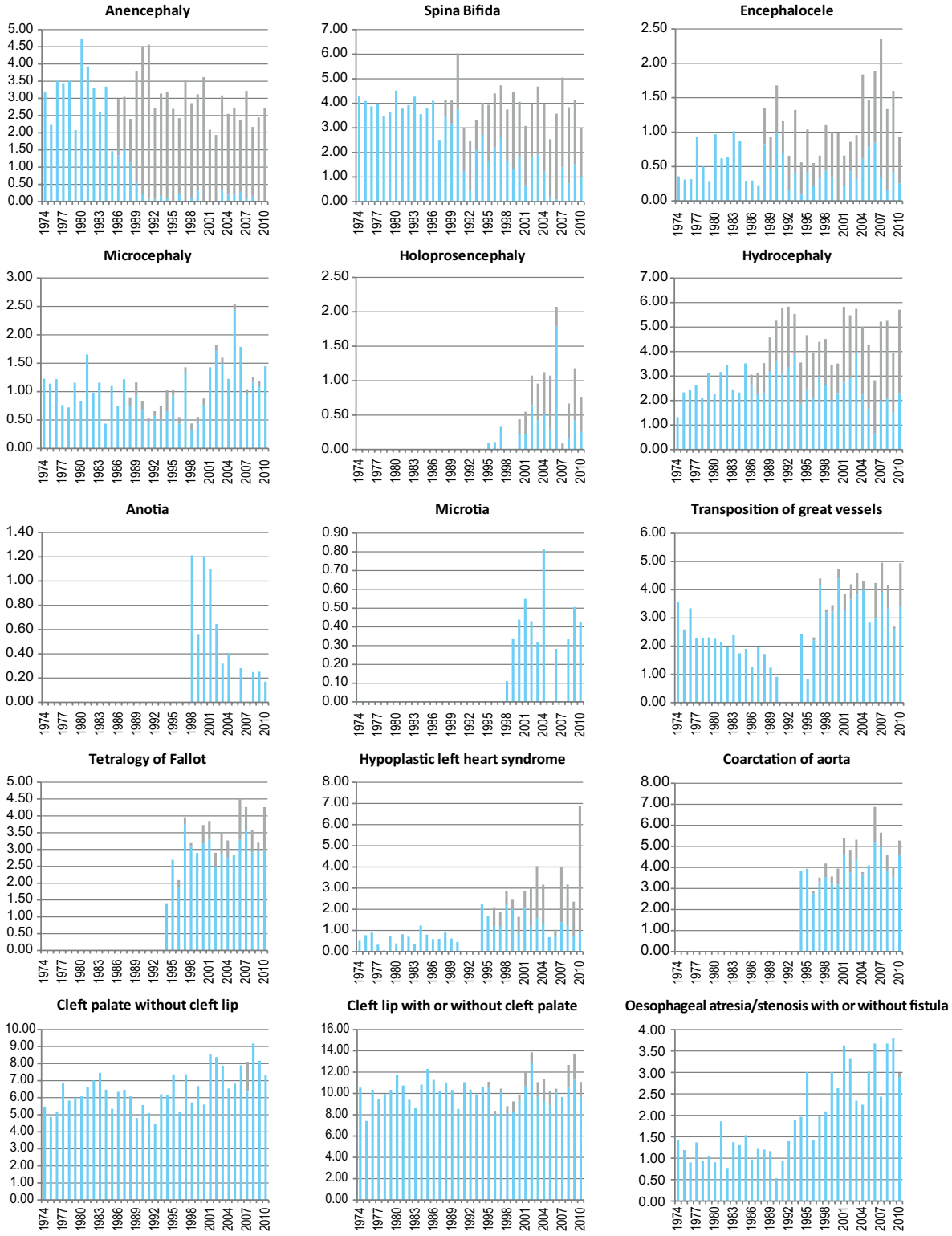
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**1,267,450**	**699,903**	**658,624**	**575,342**	**453,465**	**478,445**	**577,086**
Anencephaly	3.20	2.94	3.34	3.30	3.11	2.49	2.58
Spina bifida	3.98	3.87	4.18	3.30	4.28	3.64	3.92
Encephalocele	0.51	0.69	0.90	0.96	0.86	1.17	1.61
Microcephaly	1.02	1.07	0.97	0.78	0.77	1.73	1.33
Holoprosencephaly	nr	nr	nr	0.10*	0.18	0.96	0.94
Hydrocephaly	2.30	2.99	3.90	5.14	3.97	5.25	4.63
Anophthalmos	nr	nr	nr	nr	0.04*	0.05*	0.32*
Microphthalmos	nr	nr	nr	nr	0.18*	0.32*	0.48*
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	0.00*	0.04	0.15*
Anotia	nr	nr	nr	nr	0.99*	0.61*	0.24*
Microtia	nr	nr	nr	nr	0.29*	0.53*	0.39*
Unspecified Anotia/Microtia	nr	nr	nr	nr	6.25*	1.88	0.07
Transposition of great vessels	2.69	2.03	1.43	1.67*	3.64	3.93	4.19
Tetralogy of Fallot	nr	nr	nr	2.02*	3.18	3.26	3.95
Hypoplastic left heart syndrome	0.54	0.79	0.64	1.97*	2.18	2.72	3.54
Coarctation of aorta	nr	nr	nr	3.89*	3.62	4.66	5.23
Choanal atresia, bilateral	nr	nr	nr	0.25*	0.31	0.27*	0.80*
Cleft palate without cleft lip	5.74	6.59	5.86	5.77	6.11	7.61	8.14
Cleft lip with or without cleft palate	9.91	10.37	10.29	10.59	9.35	11.68	11.56
Oesophageal atresia/stenosis with or without fistula	1.12	1.37	1.02	1.77	2.23	2.91	3.31
Small intestine atresia/stenosis	nr	nr	nr	1.87*	2.12	3.49	3.17
Anorectal atresia/stenosis	1.36	1.16	0.62	2.00	2.87	3.89	4.25
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	3.89*	12.61	24.98*	31.59*
Hypospadias	18.60	20.40	22.36	24.06	26.40	32.50	31.43
Epispadias	nr	nr	nr	0.25*	0.55	0.37*	0.30*
Indeterminate sex	nr	nr	nr	0.29*	0.49	0.50*	0.37*
Renal agenesis	1.59	1.47	1.29	2.05	2.91	6.86	8.11
Cystic kidney	2.54	2.41	2.85	2.59	3.99	6.75	6.27
Bladder exstrophy	0.15	0.11	0.02	0.21*	0.15	0.24*	0.09*
Polydactyly, preaxial	nr	nr	12.82*	12.55	12.64	14.34	14.92
Total Limb reduction defects (include unspecified)	4.33	5.17	4.84	5.60	5.29	5.75	6.62
Transverse	nr	nr	nr	nr	nr	nr	1.83*
Preaxial	nr	nr	nr	nr	nr	nr	0.20*
Postaxial	nr	nr	nr	nr	nr	nr	0.11*
Intercalary	nr	nr	nr	nr	nr	nr	0.06*
Mixed	nr	nr	nr	nr	nr	nr	1.18*
Unspecified	nr	nr	nr	nr	nr	nr	2.27*
Diaphragmatic hernia	2.56	2.66	1.96	1.74	2.47	2.72	3.15
Omphalocele	2.34	2.14	2.63	2.10	2.29	2.74	3.02
Gastroschisis	1.06	1.41	0.99	1.15	2.87	3.05	3.21
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.00	0.02	0.00	0.09*
Prune belly sequence	nr	nr	nr	nr	nr	0.16*	0.14*
Trisomy 13	nr	nr	0.15*	0.50	0.97	1.84	1.99
Trisomy 18	nr	nr	0.46	1.51	3.18	4.62	5.20
Down syndrome, all ages (include age unknown)	8.54	7.66	8.65	11.19	14.93	17.85	21.70
<20	4.65	5.14	4.08	5.49	7.41	5.29	5.59
20-24	5.61	4.38	3.37	5.16	8.79	7.70	8.48
25-29	8.61	6.99	6.00	8.46	9.69	11.02	9.26
30-34	11.73	8.48	8.59	12.35	20.99	18.39	18.99
35-39	31.77	29.60	28.69	45.42	57.02	67.60	59.97
40-44	128.08	74.99	66.29	226.64	198.62	200.72	176.52
45+	187.27	377.36	430.11	751.88	476.19	523.56	637.68
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

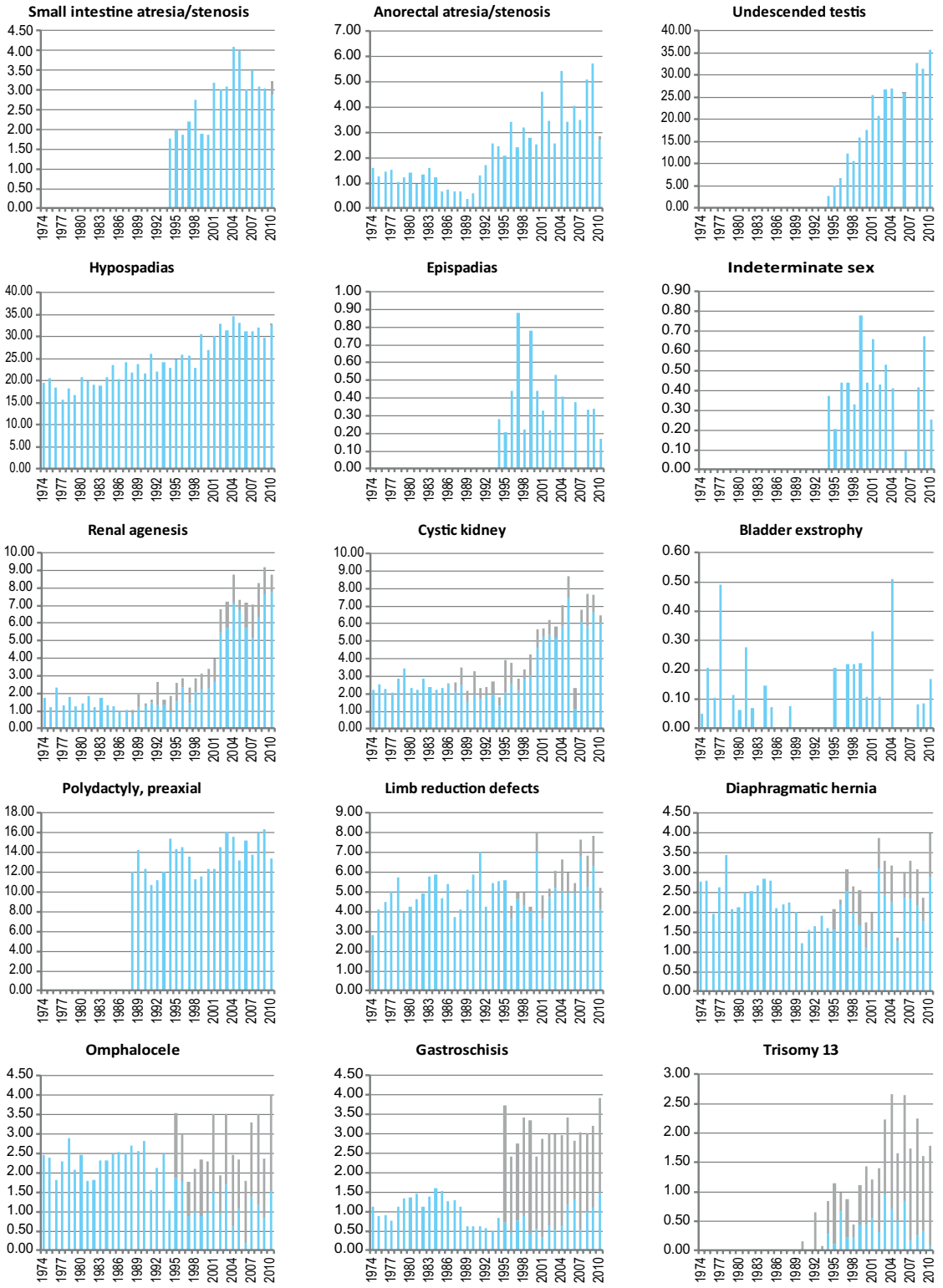
Czech Republic

Time trends 1974-2010 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

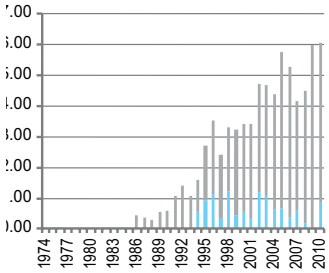
Czech Republic



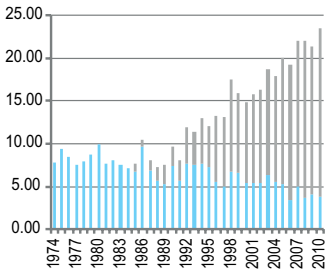
Note: L+S rates, ToP rates

Czech Republic

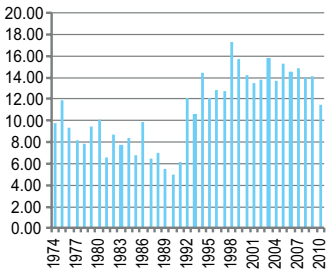
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Finland

The Finnish Register of Congenital Malformations 19.2.2012

History:
The registry was established in 1963 and regular monitoring started in 1977. It was a founding member of the ICBDSR. In 1998 the registry became an associate member of EUROCAT. The data content and the data collection practices of the registry have been revised in 1985, 1993 and 2005.

Size and coverage:
The registry is national and population based. All births in Finland are covered, at present approximately 60,000 annually. Stillbirths of 22 weeks / 500 grams or more are registered. Information on congenital anomalies is principally collected up to the age of 1 year, but later information is also included. Elective terminations of pregnancy for fetal anomalies and spontaneous abortions with congenital anomalies have been included since 1987.

Legislation and funding:
Reporting is compulsory. The registry is regulated by the act and statute on the national health care registers with personal data. The registry is run and financed by THL, National Institute for Health and Welfare (under the Ministry of Social Affairs and Health).

Sources and ascertainment:
Reports are obtained from delivery units, neonatal, paediatric and pathology departments, death certificates and cytogenetic laboratories. Case information is also received from the national Medical Birth Register, the Care Register for Health Care (including Information on Outpatient Services in Specialised Health Care), the Register on Induced Abortions and the Register of Visual Impairment, all maintained by THL, from the National Supervisory Authority for Welfare and Health (Valvira) as well as from the Cause of Death Statistics, maintained by Statistics Finland. The diagnoses of the cases with congenital anomalies received from these other sources are confirmed from the hospitals.

Exposure information:
Until 1986, extensive exposure information was obtained from maternity health centres and by personal interviews for cases with selected congenital anomalies and their controls. In 1987–1992 only parental occupation was reported. Exposure information, like maternal occupation, medication, X-rays and diseases, etc., has been obtained since 1993. Some exposure information on all births is also available in the Medical Birth Register since 1987.

Background information:
Epidemiological background data are available on all births in the Medical Birth Register and in the Statistics Finland.

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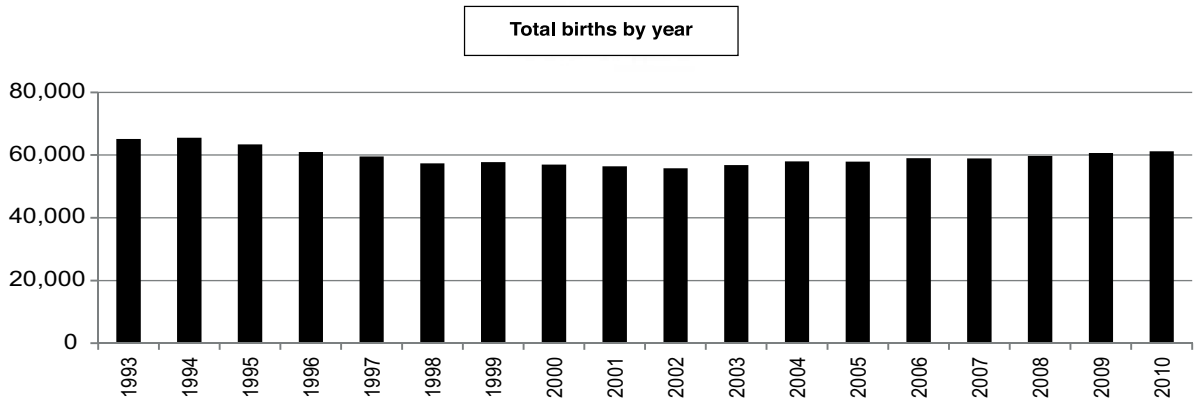
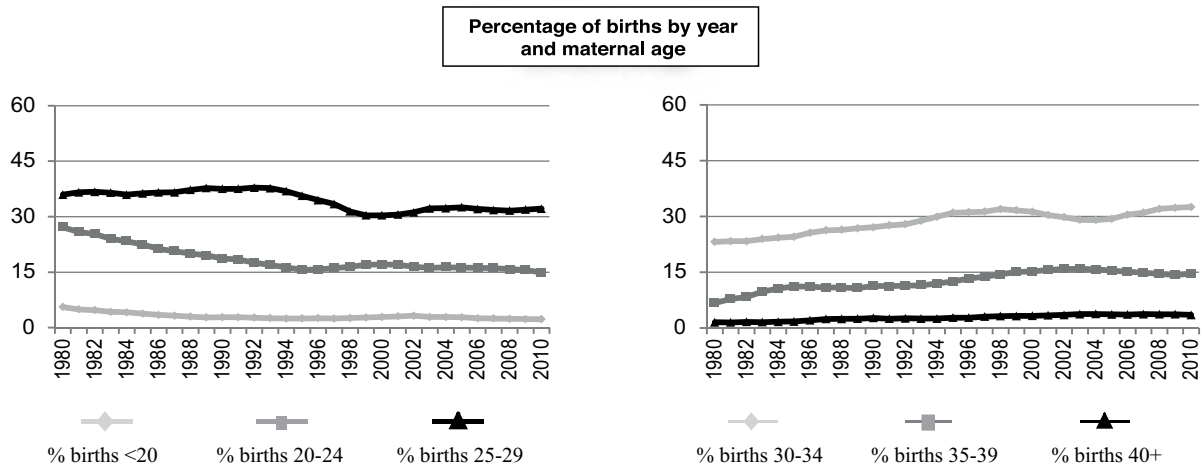
Finland





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	52	85.2	Cystic kidney	44	24.9
Spina bifida	42	48.8	Limb reduction defects	32	23.4
Encephalocele	31	81.6	Diaphragmatic hernia	19	38.0
Holoprosencephaly	18	72.0	Omphalocele	65	64.4
Hydrocephaly	35	45.5	Gastroschisis	9	18.0
Hypoplastic left heart syndrome	41	45.6	Trisomy 13	37	80.4
Cleft palate without cleft lip	19	7.3	Trisomy 18	112	83.0
Cleft lip with or without cleft palate	30	14.9	Down syndrome	314	58.5
Renal agenesis	10	38.5			

Total ToPs with births defects = 991 (Ratio ToPs/Births: 5.46 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Finland, 2010

Live births (LB)	60,980
Stillbirths (SB)	181
Total births	61,161
Number of terminations of pregnancy (ToP) for birth defects	339

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	4	14	2.94
Spina bifida	12	2	12	4.25
Encephalocele	3	2	12	2.78
Microcephaly	15	0	0	2.45
Holoprosencephaly	1	0	6	1.14
Hydrocephaly	14	0	8	3.60
Anophthalmos	3	0	0	0.49
Microphthalmos	4	0	3	1.14
Unspecified Anophthalmos/Microphthalmos	6	0	3	1.47
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	33	0	1	5.56
Transposition of great vessels	23	0	3	4.25
Tetralogy of Fallot	21	0	3	3.92
Hypoplastic left heart syndrome	23	0	13	5.89
Coarctation of aorta	70	1	2	11.94
Choanal atresia, bilateral	9	0	1	1.64
Cleft palate without cleft lip	77	0	9	14.06
Cleft lip with or without cleft palate	53	1	8	10.14
Oesophageal atresia/stenosis with or without fistula	18	0	4	3.60
Small intestine atresia/stenosis	8	0	0	1.31
Anorectal atresia/stenosis	29	1	8	6.21
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	29	0	0	4.74
Epispadias	2	0	0	0.33
Indeterminate sex	11	1	9	3.43
Renal agenesis	3	2	3	1.31
Cystic kidney	42	0	17	9.65
Bladder exstrophy	6	0	0	0.98
Polydactyly, preaxial	34	0	2	5.89
Total Limb reduction defects (include unspecified)	37	2	12	8.34
Transverse	25	1	4	4.91
Preaxial	3	1	7	1.80
Postaxial	4	0	1	0.82
Intercalary	2	0	0	0.33
Mixed	1	0	0	0.16
Unspecified	3	0	0	0.49
Diaphragmatic hernia	7	2	5	2.29
Omphalocele	12	3	22	6.05
Gastroschisis	15	0	5	3.27
Unspecified Omphalocele/Gastroschisis	29	3	29	9.97
Prune belly sequence	1	0	1	0.33
Trisomy 13	1	1	14	2.62
Trisomy 18	5	0	51	9.16
Down syndrome, all ages (include age unknown)	58	5	102	26.98
<20	1	0	1	14.45
20-24	3	0	3	6.58
25-29	13	1	10	12.20
30-34	17	2	20	19.62
35-39	16	0	47	70.30
40-44	7	2	21	148.08
45+	1	0	0	80.00
unknown	0	0	0	---

nr = not reported

Finland, Previous years rates 1993 - 2010

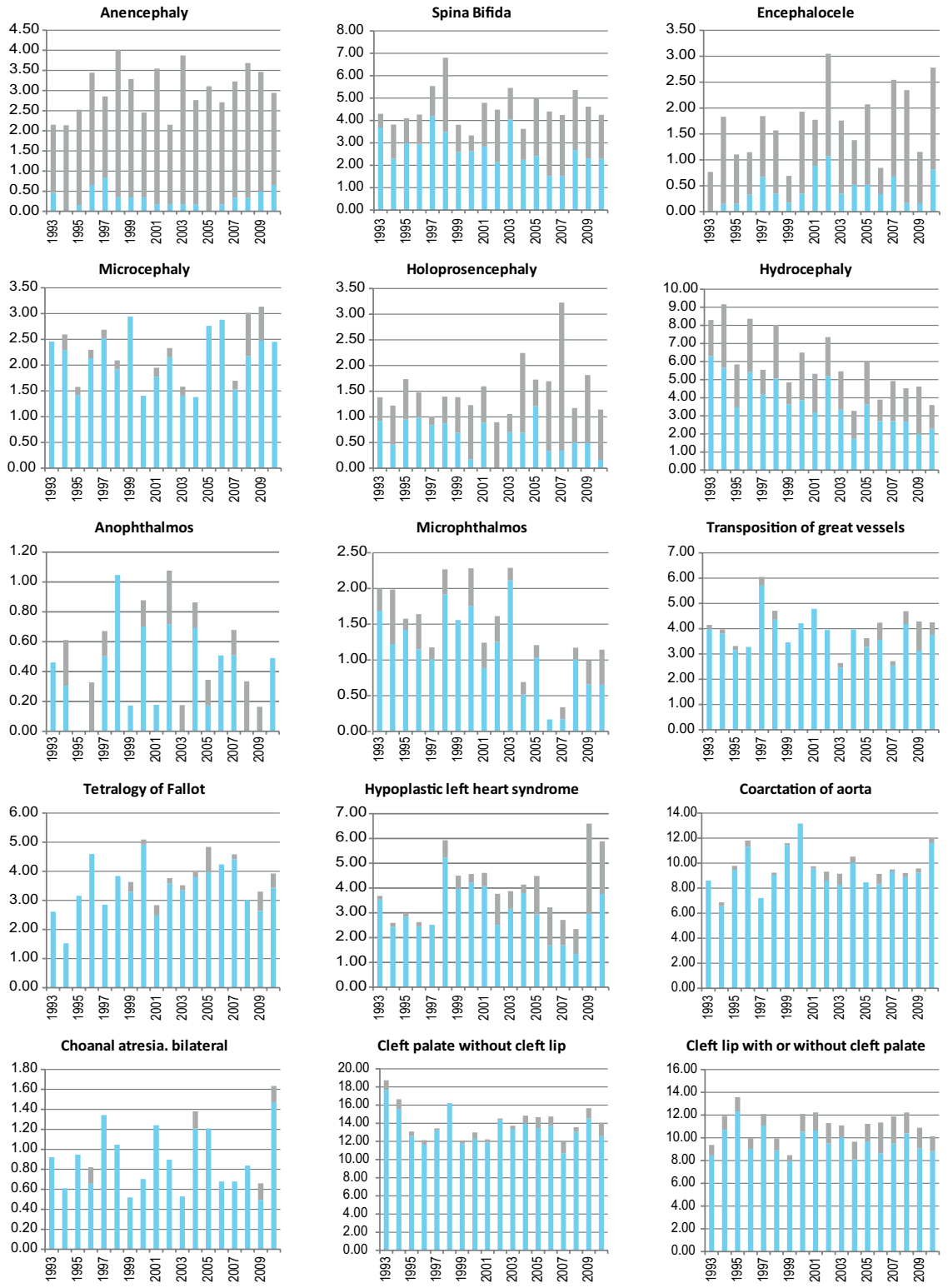
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995*	1996-2000	2001-2005	2006-2010
Total births				**193,946**	**292,630**	**284,845**	**299,481**
Anencephaly				2.27	3.21	3.09	3.21
Spina bifida				4.07	4.75	4.67	4.57
Encephalocele				1.24	1.44	2.00	1.94
Microcephaly				2.22	2.29	2.00	2.64
Holoprosencephaly				1.44	1.30	1.51	1.80
Hydrocephaly				7.79	6.66	5.48	4.31
Anophthalmos				0.36	0.62	0.53	0.43
Microphthalmos				1.86	1.78	1.40	0.77
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.00	0.30
Anotia				nr	nr	nr	nr
Microtia				nr	nr	nr	nr
Unspecified Anotia/Microtia				5.10	4.54	4.28	4.24
Transposition of great vessels				3.82	4.34	3.79	4.04
Tetralogy of Fallot				2.42	4.00	3.79	3.81
Hypoplastic left heart syndrome				3.09	4.00	4.18	4.17
Coarctation of aorta				8.40	10.59	9.44	9.88
Choanal atresia, bilateral				0.82	0.89	1.05	0.90
Cleft palate without cleft lip				16.19	13.36	14.01	14.02
Cleft lip with or without cleft palate				11.60	10.53	11.09	11.29
Oesophageal atresia/stenosis with or without fistula				3.40	3.83	3.72	4.01
Small intestine atresia/stenosis				1.24	1.03	1.09	1.07
Anorectal atresia/stenosis				5.21	5.57	4.67	5.44
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				3.35	3.31	3.55	4.47
Epispadias				0.21	0.27	0.35	0.37
Indeterminate sex				0.77	1.44	1.72	1.90
Renal agenesis				1.91	1.71	1.51	1.20
Cystic kidney				5.88	6.66	8.00	9.52
Bladder exstrophy				0.46	0.55	0.70	0.77
Polydactyly, preaxial				4.38	4.58	4.14	5.44
Total Limb reduction defects (include unspecified)				7.27	6.94	7.65	7.45
Transverse				4.38	3.66	3.83	4.51
Preaxial				1.70	1.78	2.56	1.37
Postaxial				0.21	0.44	0.49	0.53
Intercalary				0.41	0.44	0.35	0.30
Mixed				0.46	0.34	0.25	0.20
Unspecified				0.05	0.07	0.00	0.57
Diaphragmatic hernia				2.32	2.70	3.05	3.14
Omphalocele				4.18	3.86	5.34	5.44
Gastroschisis				1.70	2.56	3.41	3.17
Unspecified Omphalocele/Gastroschisis				0.21	0.27	0.32	2.54
Prune belly sequence				0.21	0.31	0.28	0.23
Trisomy 13				2.42	1.88	2.04	2.84
Trisomy 18				5.36	6.05	6.74	7.11
Down syndrome, all ages (include age unknown)				23.00	23.17	26.08	30.02
<20				18.54	6.48	8.30	11.16
20-24				6.02	7.48	7.48	9.78
25-29				12.21	9.39	11.27	12.45
30-34				17.94	17.83	16.78	22.04
35-39				56.41	53.41	58.04	66.17
40-44				177.56	173.54	181.32	198.69
45+				416.67	247.42	391.06	375.49
unknown				---	---	---	---

nr = not reported
* data include less than 5 years

Finland

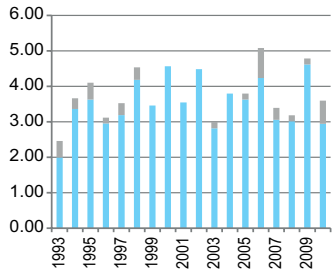
Time trends 1993-2010 (Birth prevalence rates per 10,000)



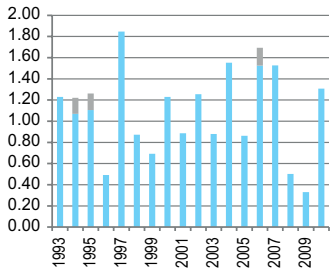
Note: L+S rates, ToP rates

Finland

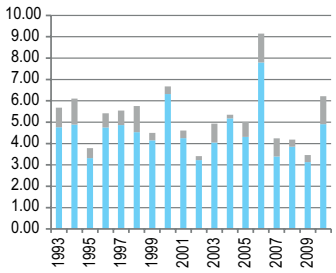
Oesophageal atresia/stenosis with or without fistula



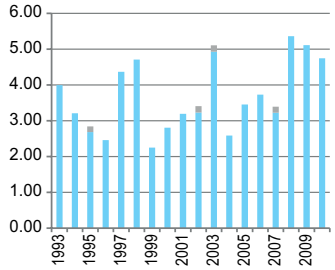
Small intestine atresia/stenosis



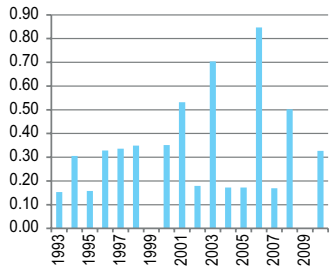
Anorectal atresia/stenosis



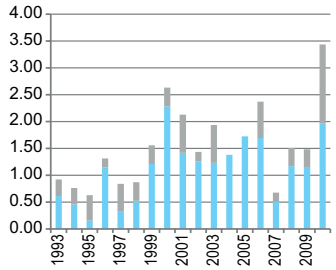
Hypospadias



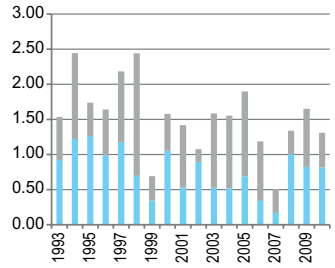
Epispadias



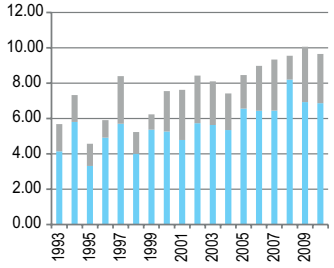
Indeterminate sex



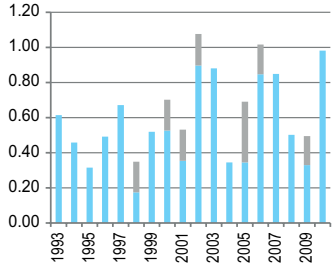
Renal agenesis



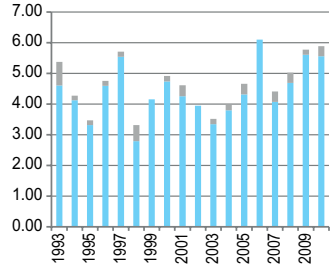
Cystic kidney



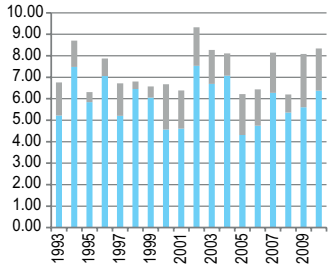
Bladder exstrophy



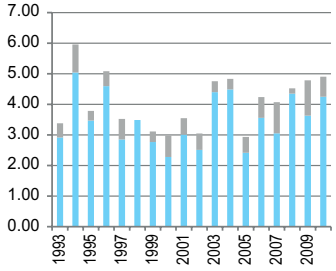
Polydactyly, preaxial



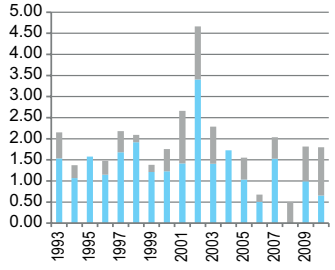
Limb reduction defects



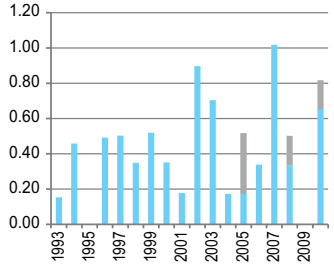
Limb reduction defects - transverse



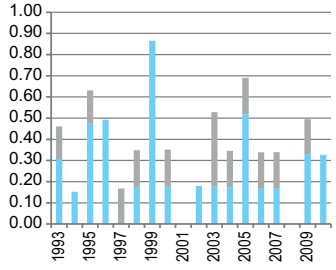
Limb reduction defects - preaxial



Limb reduction defects - postaxial

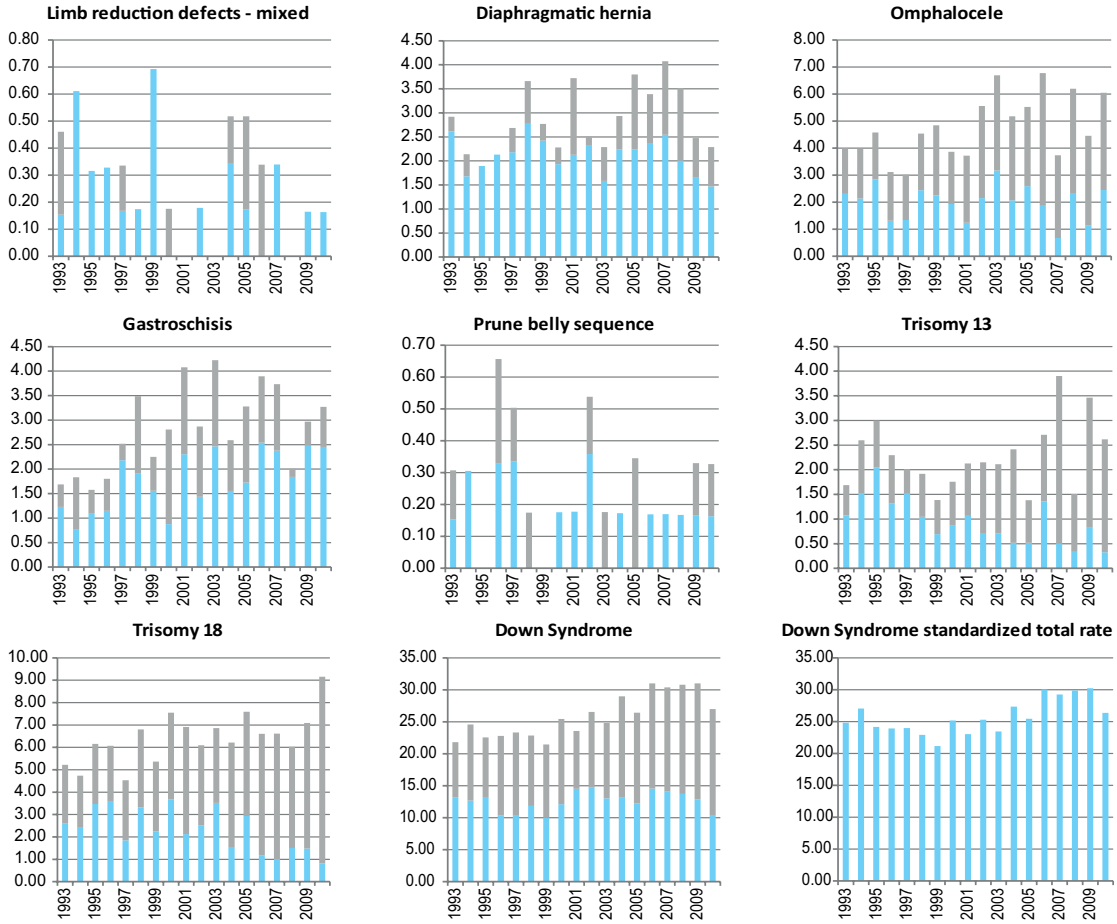


Limb reduction defects - intercalary



Note: L+S rates, ToP rates

Finland



Note: L+S rates, ToP rates

France: Paris

History:
The Programme was initiated in 1975, but the registry really started in 1981. It became an associate member of the Clearinghouse in 1982. It is also a member of EUROCAT.

Size and coverage:
The registry covers 38.000 annual births (about 5% of all births in France), that is all births (live and still births of 22 weeks or more) and terminations of pregnancy in the population of Greater Paris delivering in Paris maternity units. The estimation of the coverage of the registry is around 95%.

Legislation and funding:
The registry has been officially recognised by the French National Committee of Registries, and regularly renewed, most recently in 2008 for four years (2009-2012). The activities of the Registry are partially supported by an annual grant from INSERM and Institut de la Veille Sanitaire (Institute for Health Surveillance).

Sources of ascertainment:
Reports are actively collected from maternity units, pediatric departments, cytogenetic laboratories, pathology departments. Terminations of pregnancy are included. Case information is also received from the health certificates of the first week.

Exposure information:
Information on maternal drug use, maternal and paternal diseases and occupations, outcome of previous pregnancies, is available for the malformed cases. Data about techniques of prenatal screening (ultrasound, serum markers) and prenatal diagnosis are systematically collected.

Background information:
Background data on births are available from the National Institute of Statistics (INSEE).

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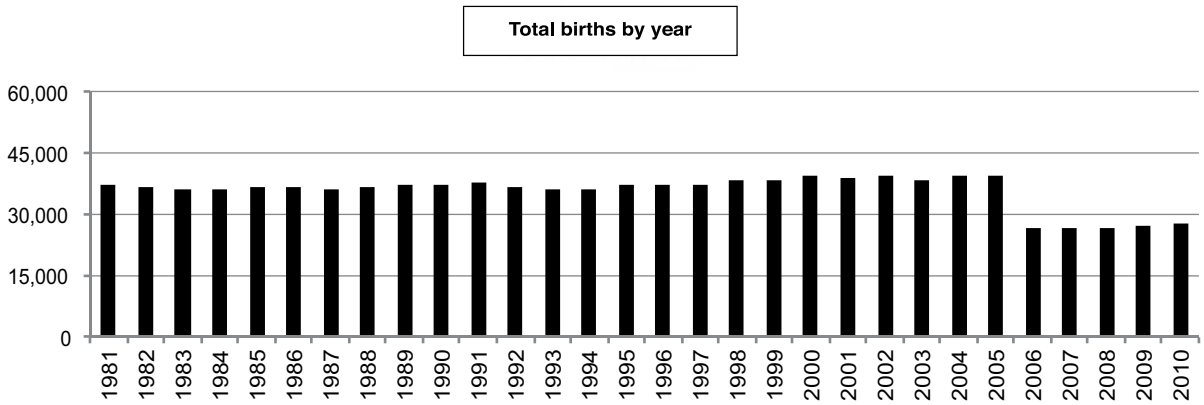
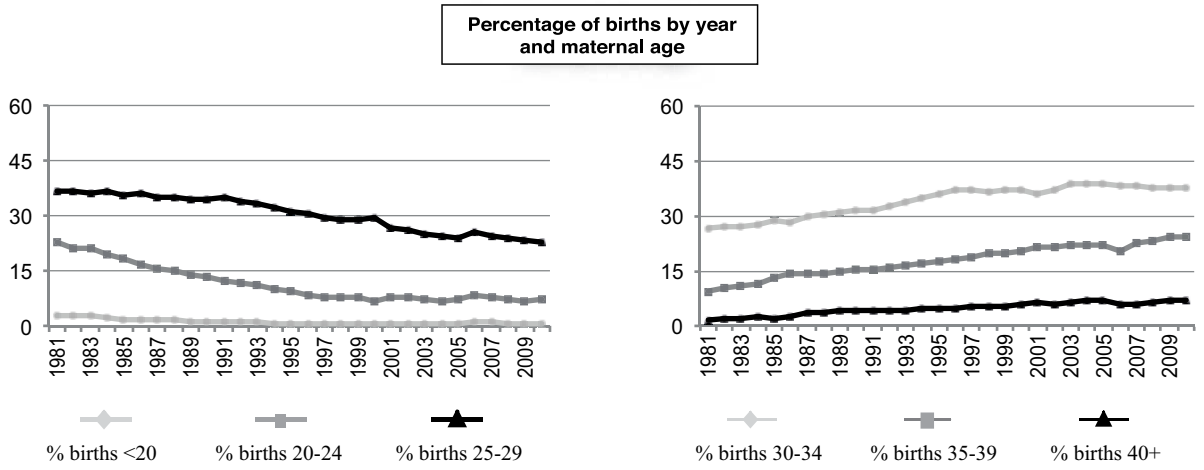




Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	42	95.5	Cystic kidney	19	22.1
Spina bifida	39	90.7	Limb reduction defects	22	42.3
Encephalocele	9	75.0	Diaphragmatic hernia	5	31.3
Holoprosencephaly	16	94.1	Omphalocele	39	79.6
Hydrocephaly	45	36.0	Gastroschisis	3	18.8
Hypoplastic left heart syndrome	15	65.2	Trisomy 13	30	96.8
Cleft palate without cleft lip	8	15.4	Trisomy 18	112	94.9
Cleft lip with or without cleft palate	22	30.1	Down syndrome	269	78.0
Renal agenesis	7	100.0			

Total ToPs with births defects = 847 (Ratio ToPs/Births: 10.44 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Paris, 2010

Live births (LB)	27,044
Stillbirths (SB)	356
Total births	27,400
Number of terminations of pregnancy (ToP) for birth defects	299

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	11	4.38
Spina bifida	2	0	11	4.74
Encephalocele	2	0	5	2.55
Microcephaly	7	0	1	2.92
Holoprosencephaly	0	0	2	0.73
Hydrocephaly	21	0	11	11.68
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	2	0.73
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	5	0	1	2.19
Microtia	2	0	1	1.09
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	3	3.65
Tetralogy of Fallot	8	1	3	4.38
Hypoplastic left heart syndrome	1	0	6	2.55
Coarctation of aorta	8	0	1	3.28
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	16	0	4	7.30
Cleft lip with or without cleft palate	19	0	5	8.76
Oesophageal atresia/stenosis with or without fistula	8	0	2	3.65
Small intestine atresia/stenosis	2	0	0	0.73
Anorectal atresia/stenosis	5	0	3	2.92
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	47	0	0	17.15
Epispadias	nr	nr	nr	nr
Indeterminate sex	0	0	2	0.73
Renal agenesis	0	0	3	1.09
Cystic kidney	20	1	8	10.58
Bladder exstrophy	0	0	1	0.36
Polydactyly, preaxial	8	0	3	4.01
Total Limb reduction defects (include unspecified)	10	0	10	7.30
Transverse	5	0	5	3.65
Preaxial	1	0	2	1.09
Postaxial	0	0	0	0.00
Intercalary	3	0	0	1.09
Mixed	1	0	3	1.46
Unspecified	0	0	0	0.00
Diaphragmatic hernia	1	0	1	0.73
Omphalocele	4	1	13	6.57
Gastroschisis	2	1	1	1.46
Unspecified Omphalocele/Gastroschisis	0	0	2	0.73
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	7	2.55
Trisomy 18	0	0	38	13.87
Down syndrome, all ages (include age unknown)	20	0	105	45.62
<20	0	0	0	0.00
20-24	3	0	1	20.52
25-29	4	0	3	11.21
30-34	2	0	22	23.20
35-39	1	0	45	68.33
40-44	9	0	34	251.61
45+	1	0	0	58.82
unknown	0	0	0	---

nr = not reported

France: Paris, Previous years rates 1981 - 2010

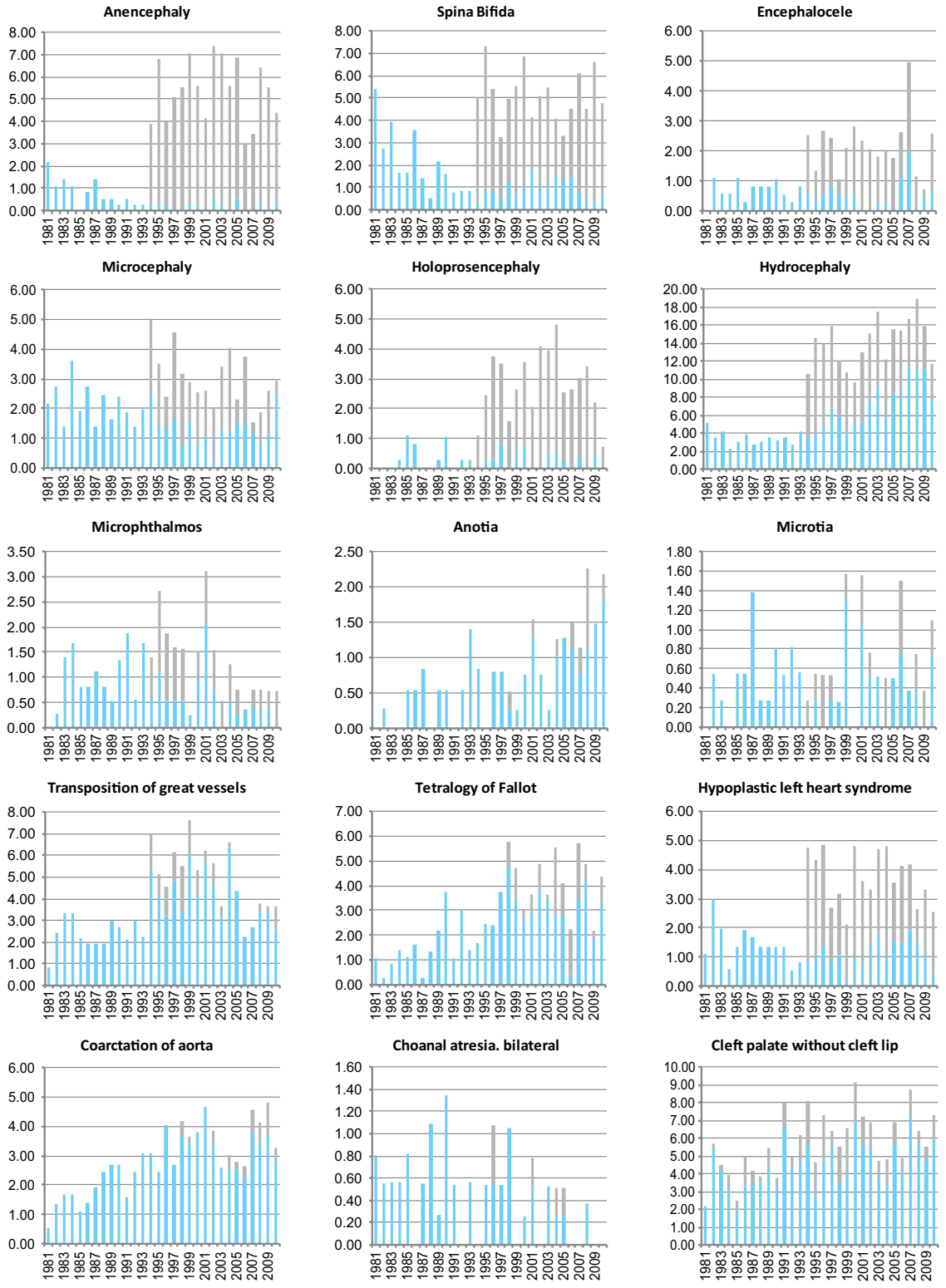
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births		**181,879**	**183,304**	**182,631**	**190,269**	**195,065**	**134,232**
Anencephaly		1.15	0.71	2.35	5.47	6.20	4.54
Spina bifida		3.08	1.85	2.96	5.20	4.41	5.29
Encephalocele		0.66	0.76	1.10	2.21	2.00	2.38
Microcephaly		2.36	2.13	2.74	3.10	2.87	2.53
Holoprosencephaly		0.27	0.44	0.82	3.00	3.49	2.38
Hydrocephaly		3.63	3.27	7.12	12.40	14.61	15.64
Anophthalmos		0.27	0.16	0.44	0.26	0.21	0.15
Microphthalmos		0.82	0.93	1.64	1.37	1.44	0.67
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.16	0.49	0.55	0.63	1.03	1.71
Microtia		0.27	0.65	0.55	0.58	0.77	0.82
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		2.42	2.29	3.89	5.83	5.28	3.20
Tetralogy of Fallot		0.93	1.85	1.92	3.94	4.36	3.87
Hypoplastic left heart syndrome		1.59	1.53	2.35	3.52	4.00	3.35
Coarctation of aorta		1.26	2.24	2.52	3.68	3.38	3.87
Choanal atresia, bilateral		0.66	0.65	0.33	0.58	0.46	0.07
Cleft palate without cleft lip		3.74	4.42	6.35	6.99	6.10	6.56
Cleft lip with or without cleft palate		6.87	7.69	9.31	9.67	7.38	9.39
Oesophageal atresia/stenosis with or without fistula		2.47	2.95	3.39	4.10	4.25	2.98
Small intestine atresia/stenosis		0.33	1.25	2.35	1.68	4.20	1.86
Anorectal atresia/stenosis		3.35	1.91	3.83	2.73	4.15	2.68
Undescended testis (36 weeks of gestation or later)		8.80	13.86	10.73	6.10	5.39*	nr
Hypospadias		9.73	12.55	14.02	10.30	15.48	15.94
Epispadias		0.16	0.71	0.38	0.37	0.41	0.75*
Indeterminate sex		1.43	1.25	1.42	1.16	1.49	0.97
Renal agenesis		0.99	1.04	2.03	2.58	3.18	1.42
Cystic kidney		1.65	3.27	6.08	9.83	10.36	10.73
Bladder exstrophy		0.33	0.16	0.77	0.58	0.41	0.97
Polydactyly, preaxial		0.66	0.98	1.86	2.31	1.33	2.16
Total Limb reduction defects (include unspecified)		nr	nr	6.78*	6.88	7.69	6.63
Transverse		nr	nr	2.44*	3.21	4.25	3.95
Preaxial		nr	nr	0.54*	1.05	1.38	1.12
Postaxial		nr	nr	0.54*	0.37	0.77	0.30
Intercalary		nr	nr	0.27*	0.58	0.41	0.45
Mixed		nr	nr	0.00*	0.47	0.56	0.52
Unspecified		nr	nr	0.00*	0.05	0.31	0.30
Diaphragmatic hernia		2.31	2.78	3.94	5.41	5.54	2.38
Omphalocele		1.59	1.85	2.79	5.10	6.25	6.03
Gastroschisis		0.60	1.04	2.19	2.89	3.23	1.42
Unspecified Omphalocele/Gastroschisis		0.49	0.27	0.38	1.05	1.03	0.60
Prune belly sequence		0.16	0.05	0.00	0.16	0.21	0.07
Trisomy 13		0.44	0.65	1.04	3.84	4.61	4.32
Trisomy 18		1.48	1.15	3.50	8.67	13.33	14.38
Down syndrome, all ages (include age unknown)		11.66	12.17	21.25	35.84	40.91	43.66
<20		10.57	13.59	5.19	11.44	18.42	0.00
20-24		6.92	6.17	8.48	16.73	10.99	10.80
25-29		7.27	5.60	9.52	15.25	13.97	16.49
30-34		11.46	12.50	14.47	22.59	22.69	24.00
35-39		24.28	28.02	41.18	55.52	63.95	63.51
40-44		50.30	24.12	115.23	201.15	191.37	232.12
45+		183.49	181.16	206.19	310.42	381.68	235.64
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

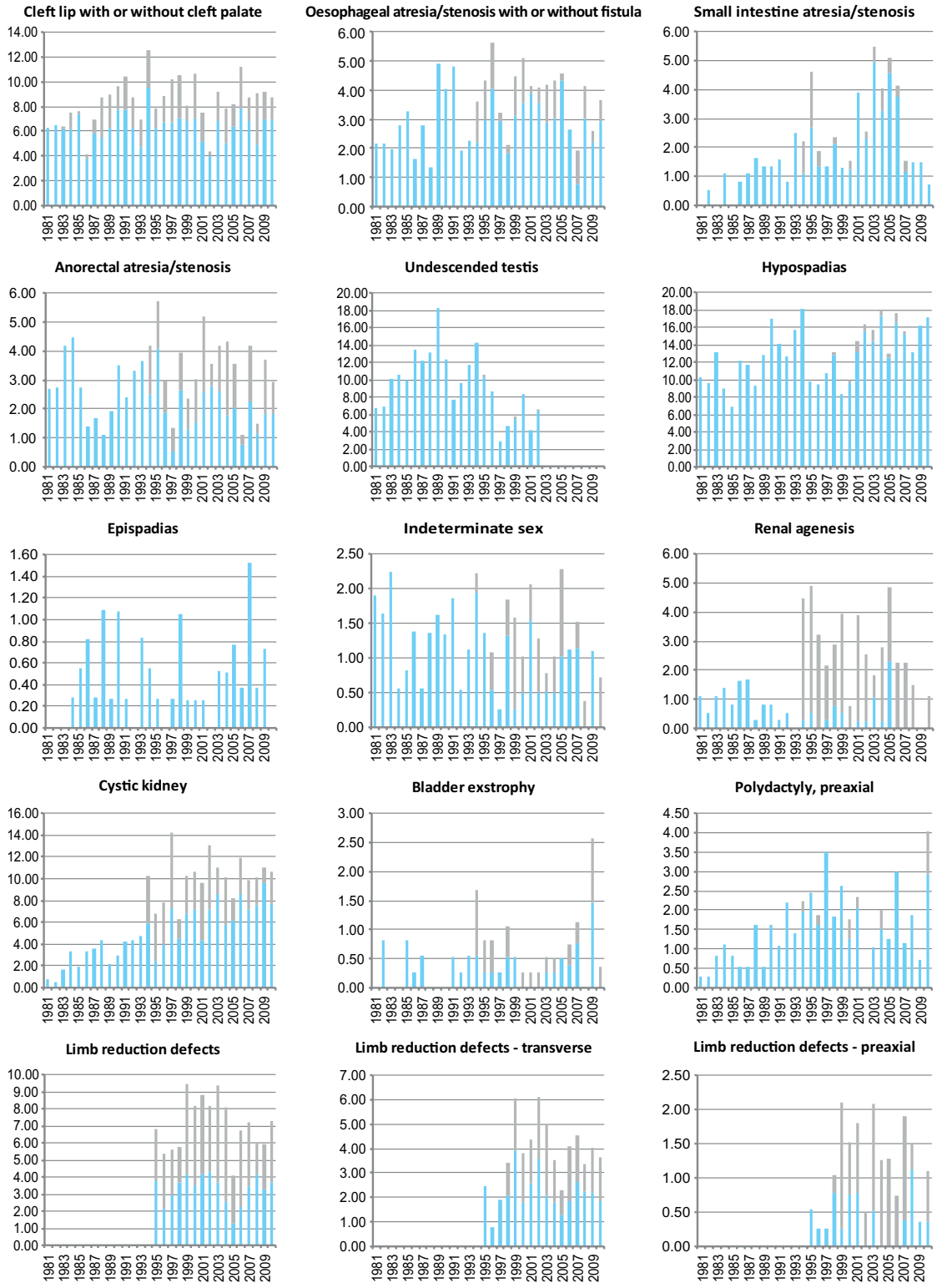
France: Paris

Time trends 1981-2010 (Birth prevalence rates per 10,000)



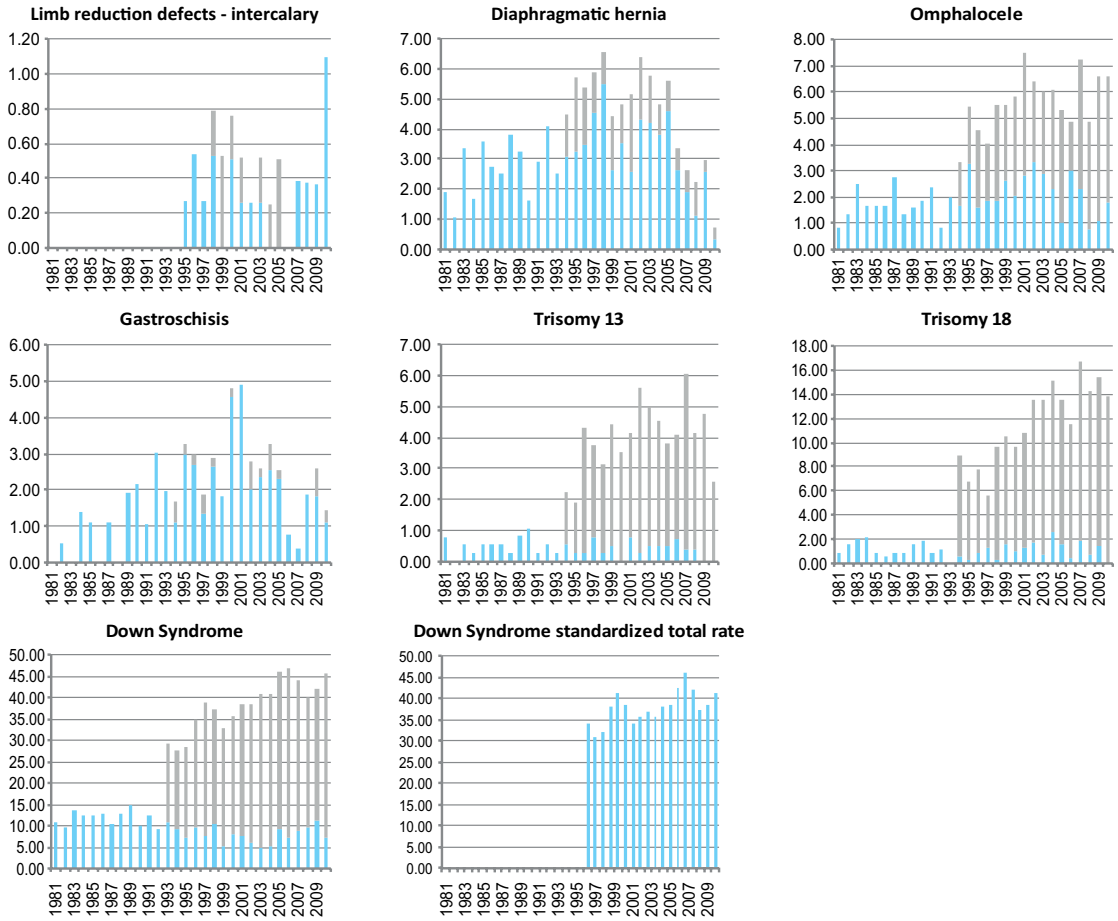
Note: L+S rates, ToP rates

France: Paris



Note: L+S rates, ToP rates

France: Paris



Note: L+S rates, ToP rates

France: REMERA

Central-East France Register of Congenital Malformation (until 2006)
Registre des Malformations en Rhône Alpes

History:
The registry began in 1973 within the Rhone-Alps area -the Auvergne region was added in 1983, the Jura area in 1985, the Côte d'Or & Nièvre in 1989 and Saône-et-Loire in 1990. The Programme was a founding member of the ICBDSR and is a full member. In 1998 the registry was split up and the Auvergne region, became financially independent, under the responsibility of Christine Francannet. The collaboration between Auvergne and the rest of the FCE-registry is maintained and common results are published. In December 2006, France Central-East Register was closed. A new register (REMERA) was created, covering part of the previous one.

Size and coverage:
The registry covers all births in the area approximately 56,000 births annually, which represents about 7% of all births in France. Stillbirths of 22 weeks or more gestation are included.

Legislation and funding:
REMERA received agreement from the French Comité National des Registres It has only public sources of funding: Ministry of Health, Region, Health authorities.

Sources of ascertainment:
The registry is population based and covers 4 French departments of Rhône-Alpes region : Rhône, Loire, Isère, Savoie. Data collection is actively performed in private ant public maternity wards and pediatric units. Other sources of information include cytogenetic laboratories, pathology laboratories, departments of medical genetics, birth certificates and data set called "Résumé Standardisé de Sortie" (similar to a "Standardized Discharge Summary"). Data is registered on a dediacated and secured server. The maximum age at postnatal diagnosis is 1 year. For children born in year x, notifications are taken into account until March x+2. We have no followup procedure. Are excluded from registration: balanced chromosomal anomalies, pyloric stenosis, metabolic disorders, minor malformations (small angiomas or naevi, hip subdislocation, small foot deformities, ill-defined facial anomalies, inguinal and umbilical hernias). Our official stillbirth definition is 22 w (28 w before 1997), which is our lower gestational age limit to include early fetal deaths/spontaneous abortions. Terminations are registered since 1985 (TOP can be performed up to full term in case of lethal or severe foetal abnormalities).

Exposure information:
Our exposure data includes drug intake in 1 st trimester of pregnancy, biological, physical and chemical hazards, medically assisted procreation, occupation. Denominators information is obtained from National institute of Statistics. We collect no controls.

Background information:
Some background information is available from the general population statistics.

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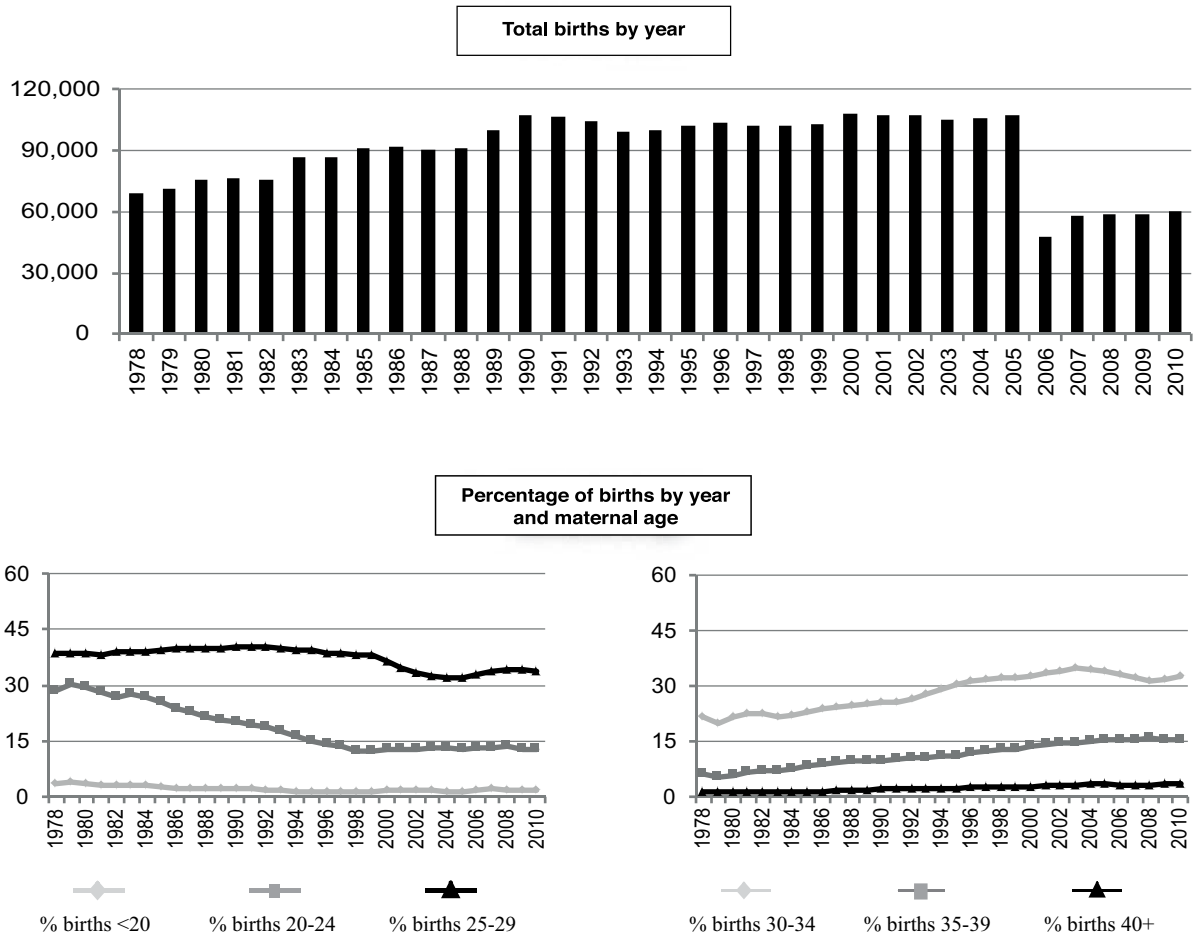
France: REMERA



Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	72	93.5	Cystic kidney	76	45.5
Spina bifida	86	90.5	Limb reduction defects	57	51.8
Encephalocele	22	95.7	Diaphragmatic hernia	16	23.9
Holoprosencephaly	44	89.8	Omphalocele	45	69.2
Hydrocephaly	90	62.1	Gastroschisis	6	12.5
Hypoplastic left heart syndrome	47	58.8	Trisomy 13	45	95.7
Cleft palate without cleft lip	19	21.3	Trisomy 18	121	99.2
Cleft lip with or without cleft palate	50	28.2	Down syndrome	395	82.0
Renal agenesis	34	33.0			

Total ToPs with births defects = 1,384 (Ratio ToPs/Births: 7.77 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: REMERA, 2010

Live births (LB)	59,477
Stillbirths (SB)	606
Total births	60,083
Number of terminations of pregnancy (ToP) for birth defects	450

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	24	4.33
Spina bifida	1	0	29	4.99
Encephalocele	0	0	8	1.33
Microcephaly	4	0	5	1.50
Holoprosencephaly	1	2	15	3.00
Hydrocephaly	20	1	24	7.49
Anophthalmos	0	0	2	0.33
Microphthalmos	1	1	5	1.17
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.17
Microtia	2	0	0	0.33
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	11	0	3	2.33
Tetralogy of Fallot	13	0	11	3.99
Hypoplastic left heart syndrome	9	1	22	5.33
Coarctation of aorta	14	0	2	2.66
Choanal atresia, bilateral	3	0	0	0.50
Cleft palate without cleft lip	26	1	6	5.49
Cleft lip with or without cleft palate	37	1	11	8.16
Oesophageal atresia/stenosis with or without fistula	19	0	2	3.50
Small intestine atresia/stenosis	6	0	0	1.00
Anorectal atresia/stenosis	2	0	0	0.33
Undescended testis (36 weeks of gestation or later)	4	0	1	0.83
Hypospadias	64	0	3	11.15
Epispadias	nr	nr	nr	nr
Indeterminate sex	2	0	0	0.33
Renal agenesis	27	2	11	6.66
Cystic kidney	36	0	29	10.82
Bladder exstrophy	1	0	3	0.67
Polydactyly, preaxial	36	0	8	7.32
Total Limb reduction defects (include unspecified)	15	1	26	6.99
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	23	1	7	5.16
Omphalocele	6	0	10	2.66
Gastroschisis	13	0	3	2.66
Unspecified Omphalocele/Gastroschisis	0	0	8	1.33
Prune belly sequence	0	0	2	0.33
Trisomy 13	0	0	12	2.00
Trisomy 18	0	0	35	5.83
Down syndrome, all ages (include age unknown)	32	0	123	25.80
<20	0	0	1	10.14
20-24	4	0	6	12.99
25-29	2	0	10	5.89
30-34	2	0	39	20.83
35-39	13	0	49	66.83
40-44	5	0	18	118.86
45+	1	0	0	84.75
unknown	5	0	0	---

nr = not reported

France: REMERA, Previous years rates 1978 - 2010

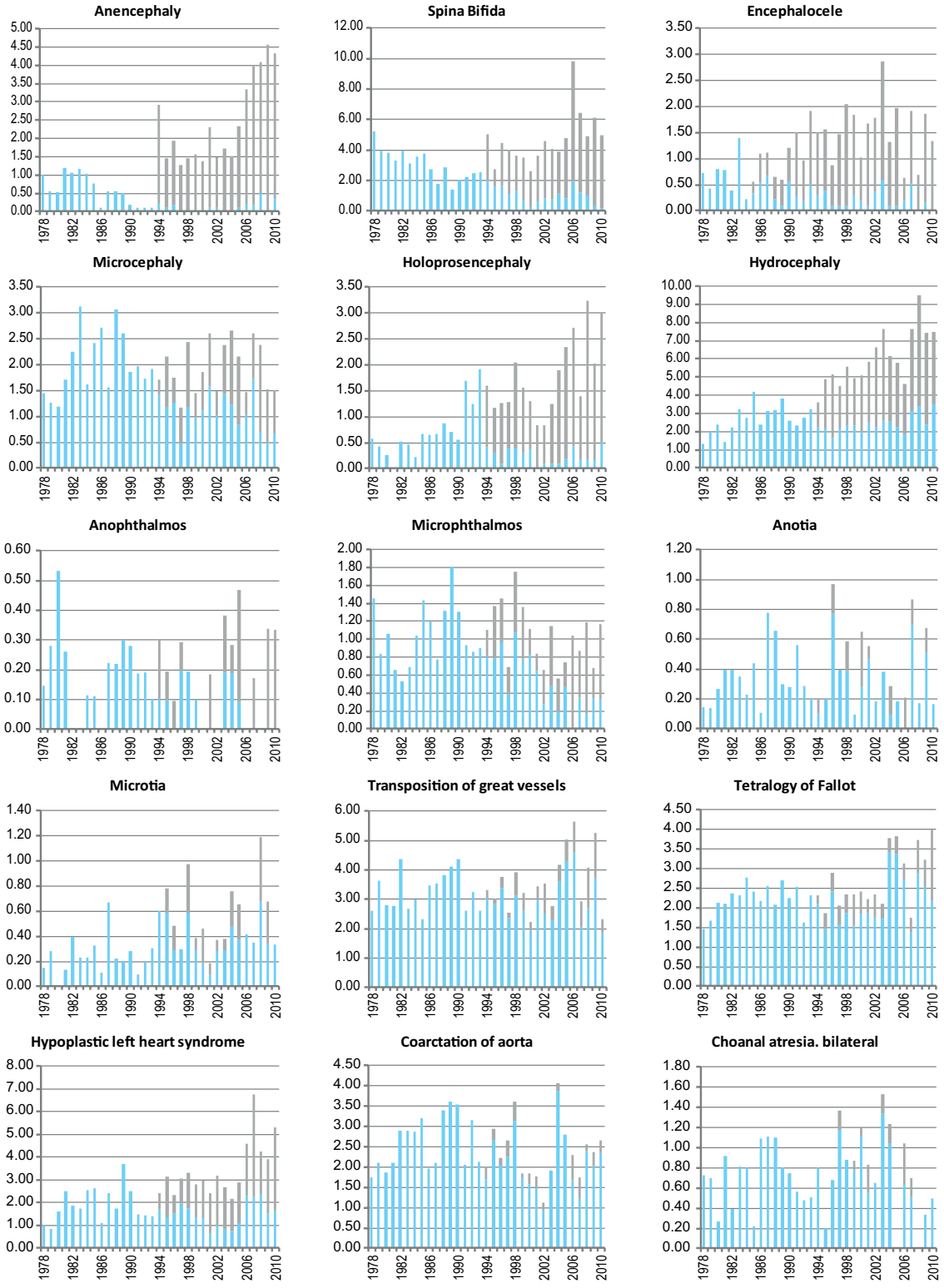
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**215,606**	**416,195**	**480,672**	**512,163**	**519,052**	**532,292**	**283,620**
Anencephaly	0.70	1.03	0.37	0.92	1.52	1.88	4.09
Spina bifida	4.31	3.53	2.14	2.99	3.62	4.19	6.31
Encephalocele	0.65	0.67	0.94	1.48	1.44	1.92	1.30
Microcephaly	1.30	2.23	2.35	1.89	1.73	2.25	1.90
Holoprosencephaly	0.42	0.38	0.69	1.52	1.48	1.43	2.47
Hydrocephaly	1.90	2.84	3.02	3.36	5.05	6.41	7.44
Anophthalmos	0.32	0.10	0.21	0.20	0.13	0.26	0.18
Microphthalmos	1.11	0.89	1.29	1.03	1.27	0.79	0.99
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.31*
Anotia	0.19	0.36	0.42	0.29	0.54	0.32	0.42
Microtia	0.14	0.26	0.29	0.39	0.52	0.47	0.60
Unspecified Anotia/Microtia	0.32	0.62	0.71	0.53	1.06	0.26	0.31*
Transposition of great vessels	3.01	2.98	3.89	2.97	3.12	3.79	3.98
Tetralogy of Fallot	1.76	2.40	2.35	2.13	2.41	2.86	3.17
Hypoplastic left heart syndrome	1.16	2.26	2.33	1.97	2.89	2.67	4.97
Coarctation of aorta	1.90	2.81	2.95	2.46	2.43	2.33	2.33
Choanal atresia, bilateral	0.56	0.62	0.96	0.51	1.00	0.85	0.49
Cleft palate without cleft lip	4.17	5.00	4.66	6.29	6.32	5.35	5.01
Cleft lip with or without cleft palate	6.86	6.42	6.20	7.52	8.05	7.06	9.77
Oesophageal atresia/stenosis with or without fistula	2.13	2.40	2.60	3.22	3.08	2.69	3.53
Small intestine atresia/stenosis	1.62	1.44	1.85	1.97	2.64	2.80	1.66
Anorectal atresia/stenosis	2.09	2.84	3.29	3.32	3.99	3.55	0.18
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	0.71
Hypospadias	6.40	6.05	9.99	9.41	12.52	11.59	11.11
Epispadias	0.19	0.19	0.29	0.12	0.31	0.13	0.18*
Indeterminate sex	0.60	0.74	0.81	0.72	0.58	0.68	0.60
Renal agenesis	0.42	0.79	0.62	0.80	1.52	1.20	5.68
Cystic kidney	0.28	1.54	2.50	3.63	4.57	4.68	8.89
Bladder exstrophy	0.23	0.17	0.33	0.41	0.31	0.34	0.46
Polydactyly, preaxial	0.70	0.82	1.46	2.15	2.08	1.35	9.77
Total Limb reduction defects (include unspecified)	4.64	4.16	4.33	4.53	5.18	4.73	6.42
Transverse	2.41	2.04	2.58	2.23	2.56	2.44	2.91*
Preaxial	0.65	0.70	0.64	0.57	0.87	1.13	1.39*
Postaxial	0.37	0.24	0.48	0.33	0.39	0.47	0.67*
Intercalary	0.42	0.60	0.27	0.55	0.44	0.32	0.63*
Mixed	0.60	0.50	0.33	0.29	0.37	0.30	0.45*
Unspecified	0.19	0.07	0.02	0.00	0.08	0.09	0.22*
Diaphragmatic hernia	1.76	2.96	2.33	2.85	2.77	3.06	3.84
Omphalocele	1.07	1.11	1.25	1.41	2.50	2.46	3.70
Gastroschisis	0.42	0.84	0.92	1.23	1.21	1.62	2.36
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.04	0.08	0.00	2.22
Prune belly sequence	0.28	0.14	0.40	0.43	0.48	0.17	0.25
Trisomy 13	0.28	0.58	1.00	1.13	1.81	2.10	2.75
Trisomy 18	0.93	0.99	1.98	3.03	4.32	4.60	6.42
Down syndrome, all ages (include age unknown)	11.87	11.05	10.96	14.70	19.96	22.56	27.33
<20	8.95	3.24	5.69	6.69	11.92	6.00	6.07
20-24	7.09	6.69	5.38	6.39	8.33	7.97	7.26
25-29	5.63	5.36	7.13	6.46	7.82	7.74	9.37
30-34	12.92	10.12	9.39	10.00	14.05	13.53	21.09
35-39	27.15	30.92	21.90	33.54	44.07	47.83	61.08
40-44	115.63	59.62	54.30	101.05	143.51	144.84	172.41
45+	123.46	112.36	110.38	294.12	273.75	231.71	260.05
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

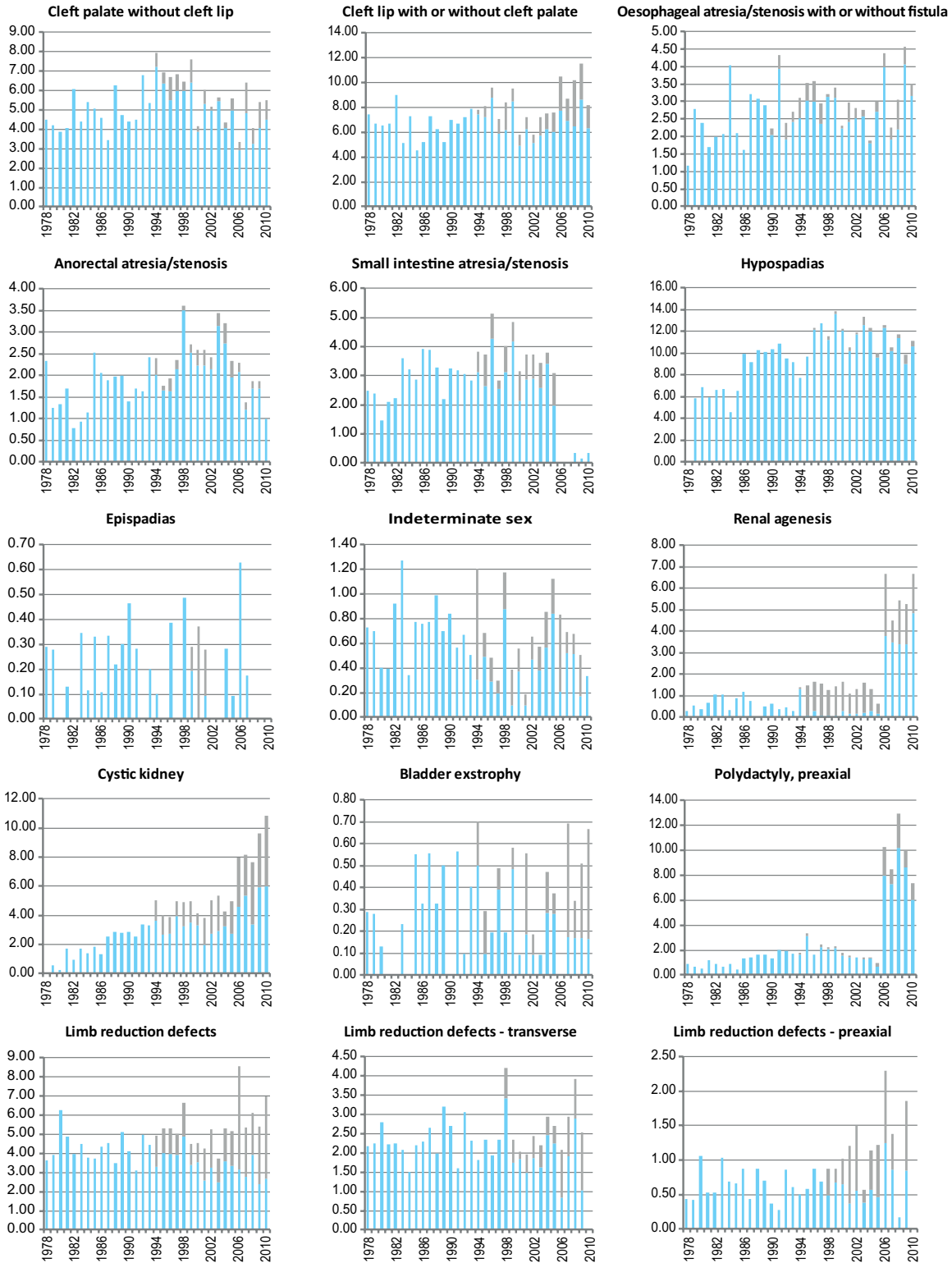
France: REMERA

Time trends 1978-2010 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

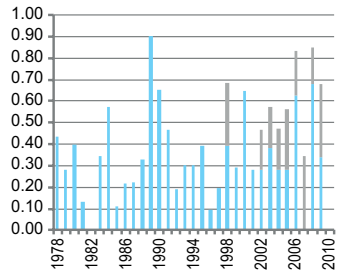
France: REMERA



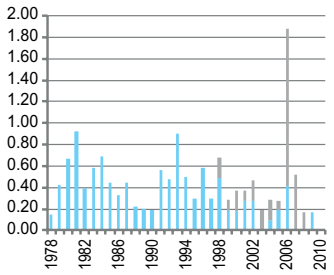
Note: L+S rates, ToP rates

France: REMERA

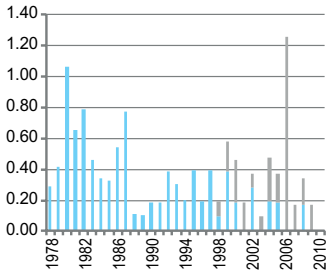
Limb reduction defects - postaxial



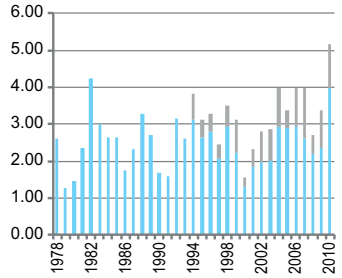
Limb reduction defects - intercalary



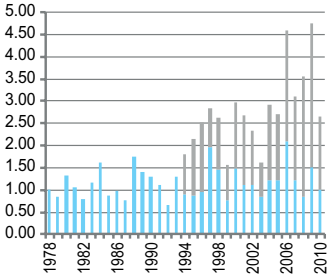
Limb reduction defects - mixed



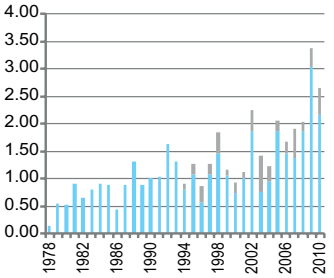
Diaphragmatic hernia



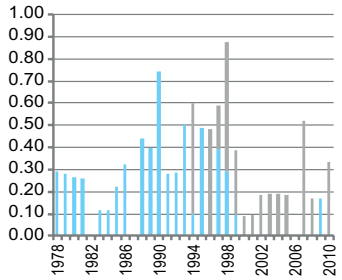
Omphalocele



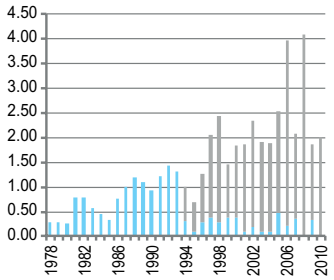
Gastroschisis



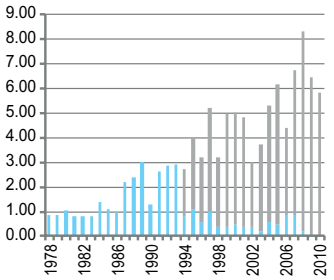
Prune belly sequence



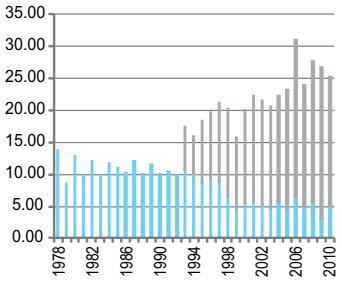
Trisomy 13



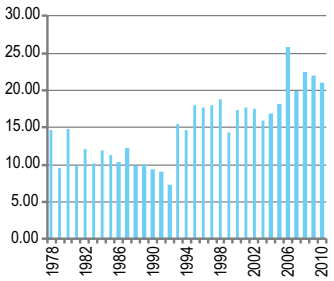
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Germany: Saxony-Anhalt
Malformation Monitoring Centre Saxony-Anhalt

History:
The birth defect registry started in 1980 in the city of Magdeburg with 4000 Births per year. After that, there was a successive enlargement of the registry from 1981-1987. Until 1987 we registered the whole area of the former "District of Magdeburg" (abput 17.000 biths per year). In 1990 there was a dramatic political change , the reunification of Germany. There has been a two-third decrease in the number of births in the registry region. So a similar process of successive territorial enlargement of the surveillance system took place. Since 2000 the system included the whole Federal State of Saxony-Anhalt (up to date 11 districts and 3 major cities). Saxony-Anhalt has currently 2.3 million inhabitants (whole Germany 81.7 million) and a birth rate 17.144 live births in 2009 (2.6% of all live born children in Germany 2009).
Additional work: since 2006 the Malformation Monitoring Centre Saxony-Anhalt is collecting and tracking the results of the newborn hearing screening in Saxony-Anhalt. The test is regular performed in the delivery units.

Legislation and funding:
1980 to 1989: Ministry of Health of the former GDR
1990 to 1992: Medical Faculty, Otto-von-Guericke University, Magdeburg
1993 to 1995: Ministry of Health, Germany
since 1995: Ministry of Labor and Social Affairs of the Federal State of Saxony-Anhalt, Germany. In addition since 2009 a new act concerning the birth defect surveillance and the primary and secondary prevention was adopted by the parliament of Saxony-Anhalt (§ 7).

Population Coverage:
The survey system is multi-centric and population-based, including all mothers resident in Saxony-Anhalt. We exclude non-residents and it is estimated that only a few percent of resident mothers would give birth outside the registry area. Saxony-Anhalt has 2.331 million inhabitants (28.03.2011) and annual births at a rate of 17.300 children (2010).

Sources of Ascertainment:
Children and fetuses with congenital anomalies diagnosed before or after birth up to one year of live are eligible for registration at the registry if the mother was resident at time of birth in Saxony-Anhalt.
Notification comes from 27 maternity units, 24 paediatric departments, 10 prenatal diagnostic centres, 8 pathology services, and 3 genetic units.

Exposure information:
Maternal and paternal occupation (in groups); occupation risk; drugs in pregnancy (ATC-code); alcohol, nicotine, drug abuse.

Background information:
Population based registry (region: Federal State Saxony-Anhalt); written informed consent of the parents are necessary. Two healthy "controls" per one malformed child are registered. Termination of pregnancy after prenatal diagnosis is legal and their are registered. Also registered are spontaneous abortions after 16th week of gestation, live and stillborn babies. Definition of stillbirth: >/= 500 grams. The maximum of age of diagnosis is 1 year of live. We do announce an annual report (see www.angeborene-fehlbildungen.com)

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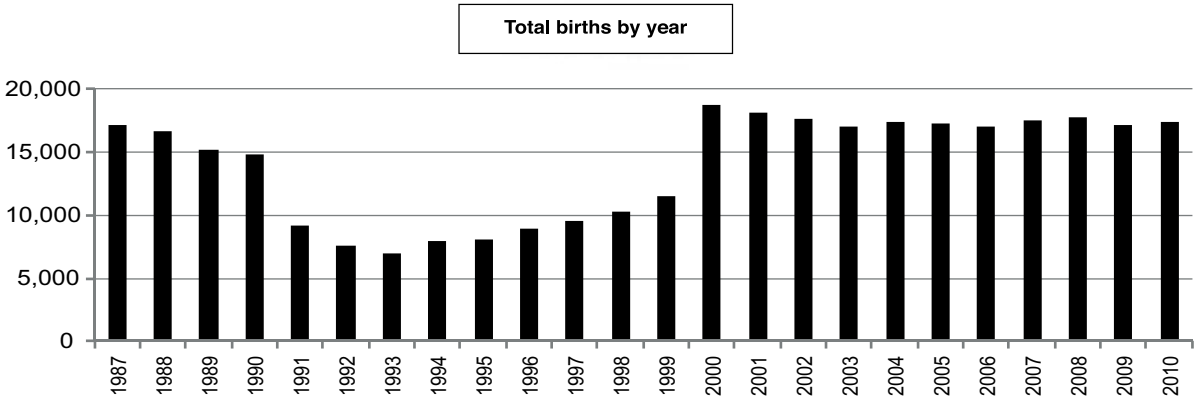
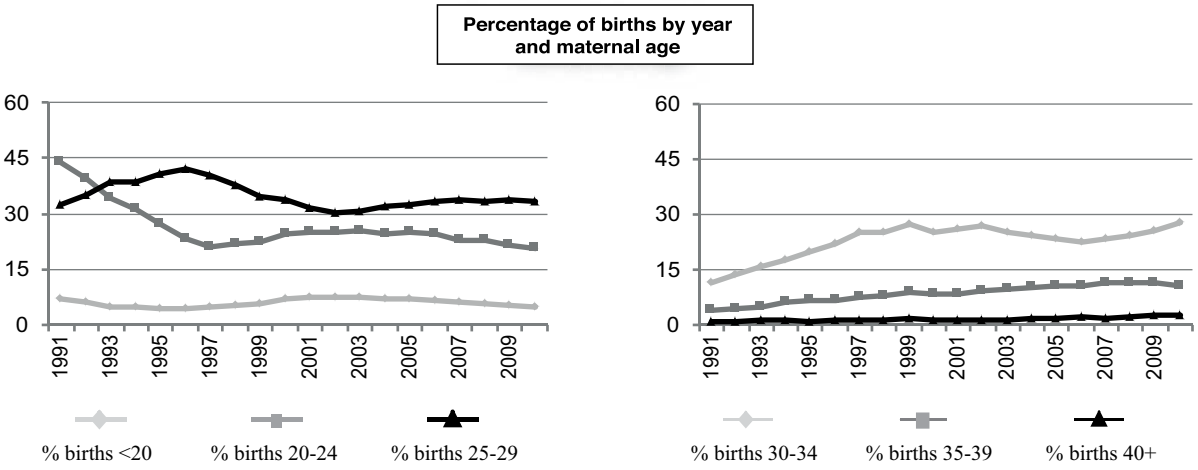
Website: www.angeborene-fehlbildungen.com

Germany: Saxony Anhalt





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	13	100.0	Cystic kidney	5	11.9
Spina bifida	24	68.6	Limb reduction defects	13	38.2
Encephalocele	4	66.7	Diaphragmatic hernia	2	11.8
Holoprosencephaly	10	90.9	Omphalocele	8	72.7
Hydrocephaly	7	33.3	Gastroschisis	2	11.8
Hypoplastic left heart syndrome	1	6.7	Trisomy 13	5	100.0
Cleft palate without cleft lip	2	7.4	Trisomy 18	22	84.6
Cleft lip with or without cleft palate	9	15.3	Down syndrome	58	61.7
Renal agenesis	6	37.5			

Total ToPs with births defects = 283 (Ratio ToPs/Births: 5.41 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Germany: Saxony Anhalt, 2010

Live births (LB)	17,300
Stillbirths (SB)	63
Total births	17,363
Number of terminations of pregnancy (ToP) for birth defects	92

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	2	1.15
Spina bifida	3	0	3	3.46
Encephalocele	1	0	1	1.15
Microcephaly	22	3	1	14.97
Holoprosencephaly	1	0	7	4.61
Hydrocephaly	7	0	3	5.76
Anophthalmos	1	0	2	1.73
Microphthalmos	0	0	1	0.58
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.58
Microtia	3	0	0	1.73
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	1	0	0	0.58
Tetralogy of Fallot	6	0	1	4.03
Hypoplastic left heart syndrome	1	0	0	0.58
Coarctation of aorta	8	0	2	5.76
Choanal atresia, bilateral	3	0	0	1.73
Cleft palate without cleft lip	8	0	0	4.61
Cleft lip with or without cleft palate	19	0	7	14.97
Oesophageal atresia/stenosis with or without fistula	3	1	1	2.88
Small intestine atresia/stenosis	1	0	0	0.58
Anorectal atresia/stenosis	11	1	0	6.91
Undescended testis (36 weeks of gestation or later)	8	1	0	5.18
Hypospadias	14	0	1	8.64
Epispadias	1	0	0	0.58
Indeterminate sex	1	0	0	0.58
Renal agenesis	1	0	1	1.15
Cystic kidney	16	0	3	10.94
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	9	0	1	5.76
Total Limb reduction defects (include unspecified)	6	1	2	5.18
Transverse	1	0	0	0.58
Preaxial	3	1	2	3.46
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	2	0	0	1.15
Unspecified	0	0	0	0.00
Diaphragmatic hernia	4	0	0	2.30
Omphalocele	2	0	3	2.88
Gastroschisis	6	0	1	4.03
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	2	1.15
Trisomy 18	1	0	9	5.76
Down syndrome, all ages (include age unknown)	12	1	21	19.58
<20	0	0	0	0.00
20-24	0	0	0	0.00
25-29	2	0	2	6.94
30-34	3	1	4	16.61
35-39	2	0	7	48.70
40-44	4	0	7	246.64
45+	1	0	1	1,333.33
unknown	0	0	0	---

Germany: Saxony Anhalt, Previous years rates 1980 - 2010

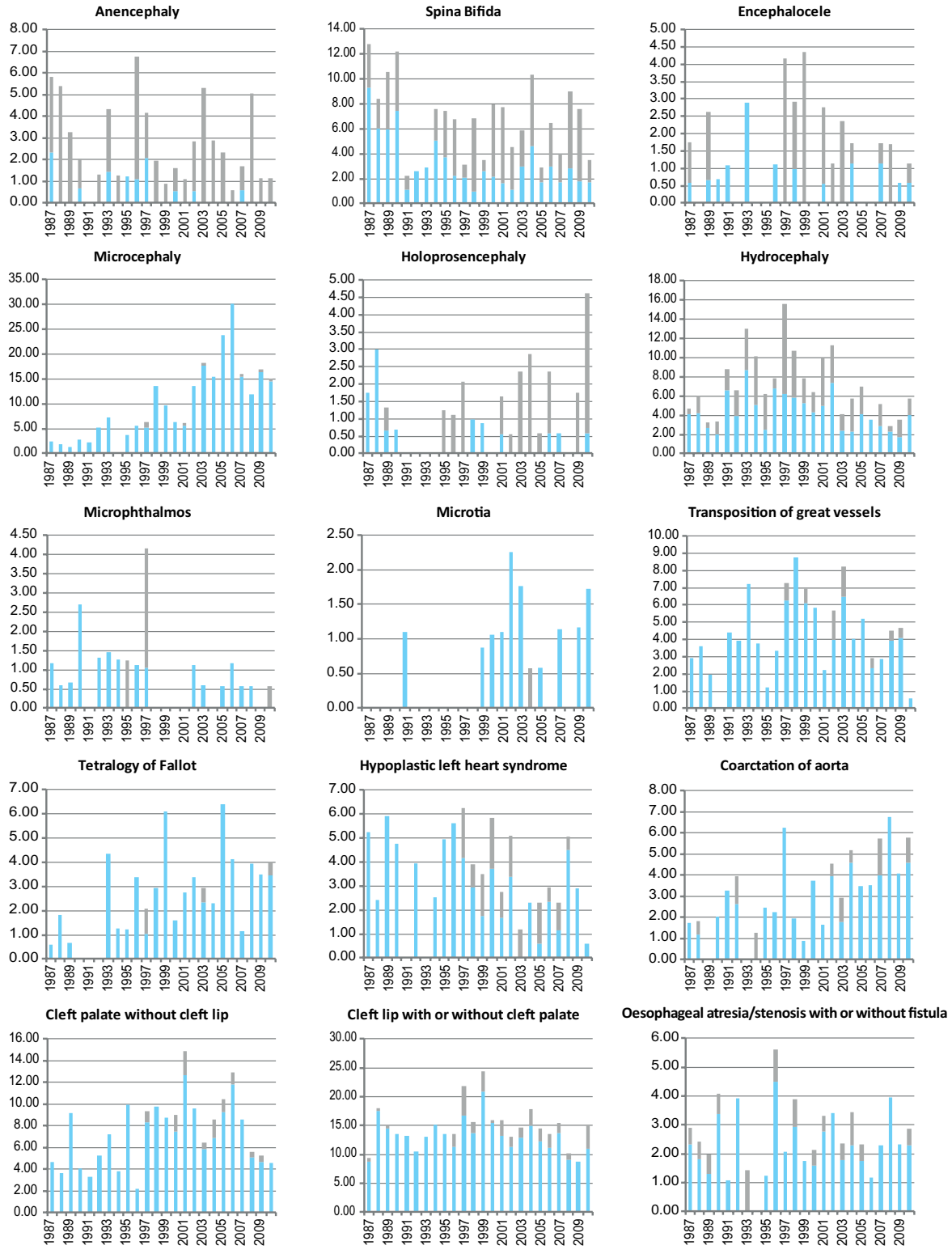
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**18,113**	**87,531**	**80,602**	**39,659**	**59,053**	**87,458**	**86,793**
Anencephaly	0.55	2.40	3.47	1.51	2.71	2.86	1.96
Spina bifida	1.10	5.48	11.17	4.54	5.93	6.29	6.11
Encephalocele	0.00	0.57	1.36	0.76	2.20	1.60	1.04
Microcephaly	nr	nr	2.04*	3.53	8.13	15.32	17.86
Holoprosencephaly	nr	nr	1.72*	0.25	0.85	1.60	1.84
Hydrocephaly	nr	nr	4.39*	8.83	9.14	7.66	4.15
Anophthalmos	nr	nr	0.00*	1.01	0.00	0.23	0.46
Microphthalmos	nr	nr	1.25*	1.01	0.85	0.46	0.58
Unspecified Anophthalmos/Microphthalmos	nr	nr	0.00*	0.00	0.00	0.00	0.00
Anotia	nr	nr	0.00*	0.25	0.00	0.34	0.35
Microtia	nr	nr	0.00*	0.25	0.51	1.26	0.81
Unspecified Anotia/Microtia	nr	nr	0.00*	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	nr	2.20*	4.03	6.43	5.03	3.11
Tetralogy of Fallot	nr	nr	0.78*	1.26	3.05	3.54	3.34
Hypoplastic left heart syndrome	nr	nr	4.55*	2.27	5.08	2.74	2.77
Coarctation of aorta	nr	nr	1.41*	2.27	3.05	3.54	5.18
Choanal atresia, bilateral	nr	nr	0.78*	1.51	1.19	0.46	0.35
Cleft palate without cleft lip	nr	nr	5.33*	5.80	8.13	10.06	7.37
Cleft lip with or without cleft palate	nr	nr	13.96*	13.11	18.12	15.21	12.56
Oesophageal atresia/stenosis with or without fistula	nr	nr	2.82*	1.51	2.88	2.97	2.53
Small intestine atresia/stenosis	nr	nr	1.25*	3.28	1.69	2.29	1.27
Anorectal atresia/stenosis	nr	nr	3.61*	3.53	2.37	3.09	7.03
Undescended testis (36 weeks of gestation or later)	nr	nr	11.45*	19.67	12.02	10.75	5.42
Hypospadias	nr	nr	13.02*	20.93	15.41	8.35	7.14
Epispadias	nr	nr	0.31*	0.50	0.51	0.23	0.58
Indeterminate sex	nr	nr	0.47*	0.00	1.19	0.57	0.35
Renal agenesis	nr	nr	1.57*	1.51	2.71	2.06	2.19
Cystic kidney	nr	nr	2.04*	4.79	3.05	6.97	8.64
Bladder exstrophy	nr	nr	0.78*	0.25	0.34	0.23	0.12
Polydactyly, preaxial	nr	nr	0.47*	3.03	3.22	3.54	5.53
Total Limb reduction defects (include unspecified)	nr	nr	5.96*	5.30	8.64	7.20	7.03
Transverse	nr	nr	nr	nr	4.79*	2.63	1.38
Preaxial	nr	nr	nr	nr	0.00*	0.57	1.27
Postaxial	nr	nr	nr	nr	0.00*	0.00	0.58
Intercalary	nr	nr	nr	nr	1.59*	1.60	0.12
Mixed	nr	nr	nr	nr	1.59*	1.72	2.88
Unspecified	nr	nr	nr	nr	0.00*	0.69	0.81
Diaphragmatic hernia	nr	nr	1.88*	0.50	1.69	2.63	3.11
Omphalocele	nr	nr	5.33*	1.26	3.39	3.54	2.65
Gastroschisis	nr	nr	1.10*	2.52	3.39	4.34	3.69
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	0.53*	0.00	0.23
Prune belly sequence	nr	nr	0.16*	1.01	1.02	0.91	0.23
Trisomy 13	0.00	0.34	0.50	0.50	2.03	0.80	1.27
Trisomy 18	0.55	1.03	0.87	1.26	1.35	3.89	4.15
Down syndrome, all ages (include age unknown)	5.52	8.80	8.81	11.60	16.93	15.44	17.63
<20	nr	nr	nr	nr	0.00*	6.27	0.00
20-24	nr	nr	nr	nr	4.37*	5.99	9.78
25-29	nr	nr	nr	nr	11.04*	8.40	6.89
30-34	nr	nr	nr	nr	14.94*	10.94	16.83
35-39	nr	nr	nr	nr	71.20*	49.04	47.50
40-44	nr	nr	nr	nr	120.48*	174.51	146.90
45+	nr	nr	nr	nr	0.00*	392.16	519.48
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

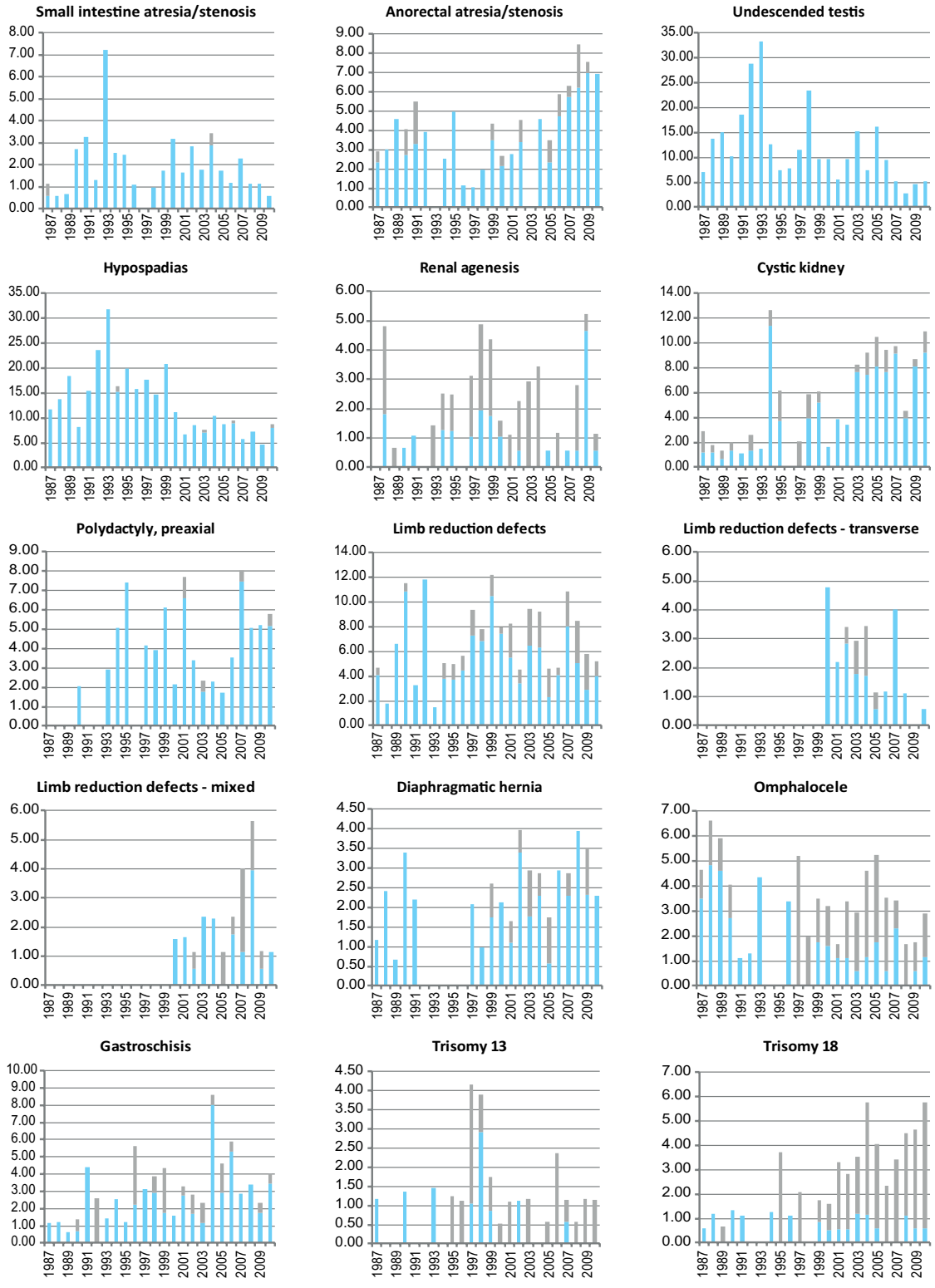
Germany: Saxony Anhalt

Time trends 1987-2010 (Birth prevalence rates per 10,000)



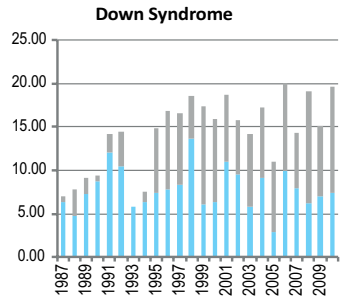
Note: L+S rates, ToP rates

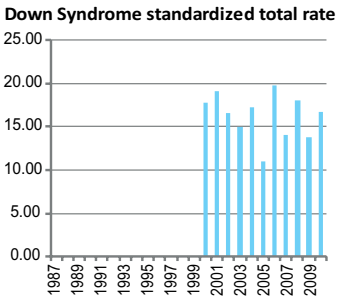
Germany: Saxony Anhalt



Note: L+S rates, ToP rates

Germany: Saxony Anhalt





Note: L+S rates, ToP rates

Hungary
Hungarian Congenital Abnormality Registry

History:
Centralized registration of congenital abnormalities began in Hungary in 1962, and came under our co-ordination in 1970. Monitoring began in 1973. The Programme was a founding member of the International Clearinghouse.

Size and coverage:
The registry covers all births in Hungary, approximately 100,000 annually. Criteria to define stillbirth was changed in 1998. At present, stillbirths of at least 24 weeks gestation or 500 grams are registered. Prenatally diagnosed and terminated fetuses are also registered.

Legislation and funding:
Reporting is compulsory. The registry is currently run and financed by the National Center for Healthcare Audit and Improvement; formerly by the National Center for Epidemiology, and the National Institute of Public Health.

Sources of ascertainment:
Reports are obtained from multiple sources, such as delivery units, neonatal and pediatric surgery, pathology, and prenatal diagnostic centers. Abnormalities detected before the age of one are reported Variations in figures (especially in the1990s) may reflect incomplete notification.

Exposure information:
Exposure information has been available since 1980, when a case-control system was initiated. Mothers of selected malformed infants and controls are interviewed by community nurses to collect information.

Background information:
General background information on all births is available from central statistics. The online notification (instead of paper-based) has started since 15th of October 2009.

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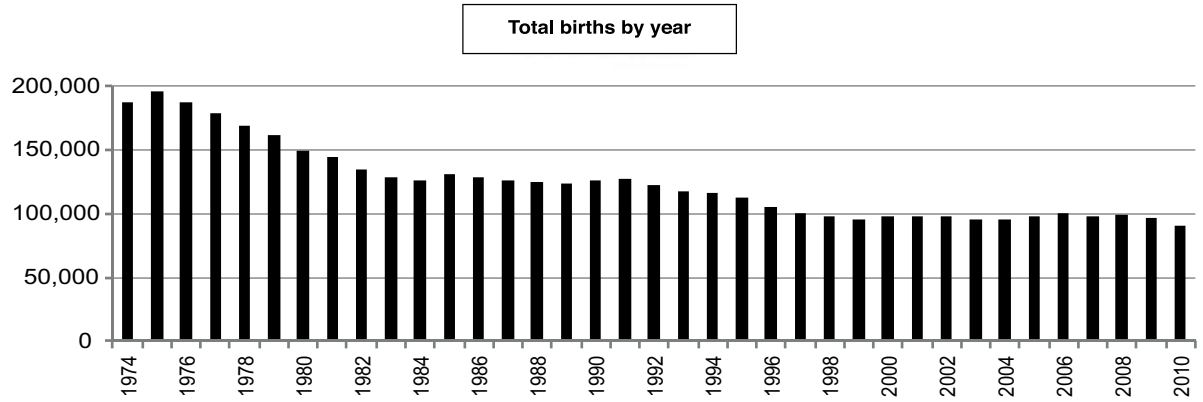
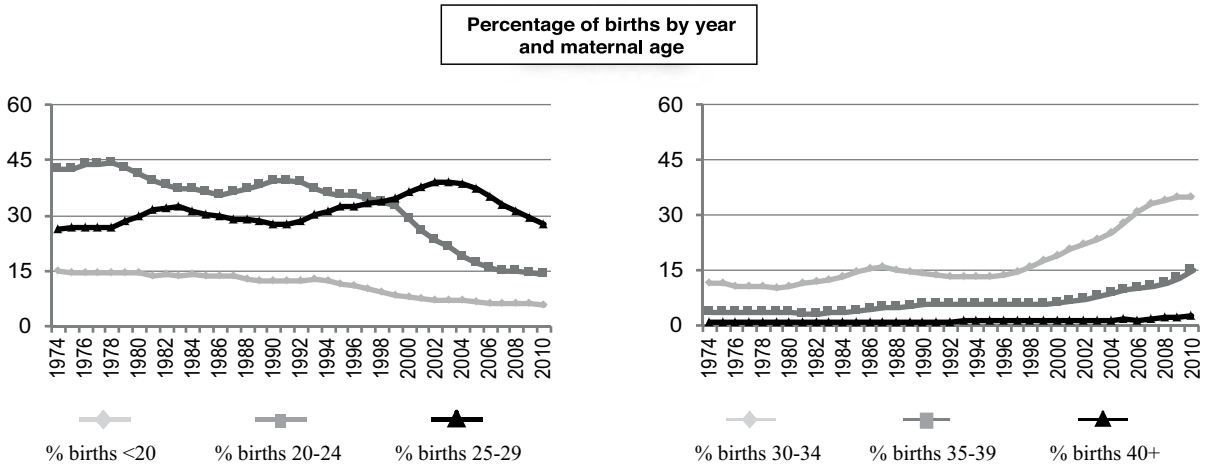




Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	45	90.0	Cystic kidney	35	25.4
Spina bifida	72	60.5	Limb reduction defects	21	17.2
Encephalocele	20	74.1	Diaphragmatic hernia	15	16.9
Holoprosencephaly	15	55.6	Omphalocele	26	50.0
Hydrocephaly	76	38.0	Gastroschisis	25	83.3
Hypoplastic left heart syndrome	21	27.6	Trisomy 13	37	80.4
Cleft palate without cleft lip	6	3.3	Trisomy 18	76	78.4
Cleft lip with or without cleft palate	28	11.6	Down syndrome	321	55.6
Renal agenesis	16	38.1			

Total ToPs with births defects = 1,331 (Ratio ToPs/Births: 4.63 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Hungary, 2010

Live births (LB)	90,335
Stillbirths (SB)	387
Total births	90,722
Number of terminations of pregnancy (ToP) for birth defects	440

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	7	0.88
Spina bifida	13	0	17	3.31
Encephalocele	2	0	7	0.99
Microcephaly	20	0	0	2.20
Holoprosencephaly	0	0	1	0.11
Hydrocephaly	30	1	18	5.40
Anophthalmos	4	0	0	0.44
Microphthalmos	12	0	0	1.32
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	3	0	0	0.33
Microtia	1	0	0	0.11
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	27	0	1	3.09
Tetralogy of Fallot	31	0	2	3.64
Hypoplastic left heart syndrome	18	0	5	2.54
Coarctation of aorta	28	0	0	3.09
Choanal atresia, bilateral	9	0	0	0.99
Cleft palate without cleft lip	63	0	6	7.61
Cleft lip with or without cleft palate	68	0	8	8.38
Oesophageal atresia/stenosis with or without fistula	28	1	0	3.20
Small intestine atresia/stenosis	21	0	1	2.42
Anorectal atresia/stenosis	39	0	0	4.30
Undescended testis (36 weeks of gestation or later)	162	0	0	17.86
Hypospadias	311	0	0	34.28
Epispadias	2	0	0	0.22
Indeterminate sex	6	0	0	0.66
Renal agenesis	1	0	2	0.33
Cystic kidney	24	0	2	2.87
Bladder exstrophy	3	0	0	0.33
Polydactyly, preaxial	84	0	1	9.37
Total Limb reduction defects (include unspecified)	25	1	6	3.53
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	24	0	6	3.31
Omphalocele	6	0	5	1.21
Gastroschisis	0	0	5	0.55
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	14	1.76
Trisomy 18	4	0	26	3.31
Down syndrome, all ages (include age unknown)	68	0	120	20.72
<20	1	0	1	3.78
20-24	5	0	1	4.74
25-29	12	0	11	9.17
30-34	14	0	21	11.11
35-39	28	0	59	64.74
40-44	8	0	22	132.10
45+	0	0	5	602.41
unknown	0	0	0	---

nr = not reported

Hungary, Previous years rates 1974 - 2010

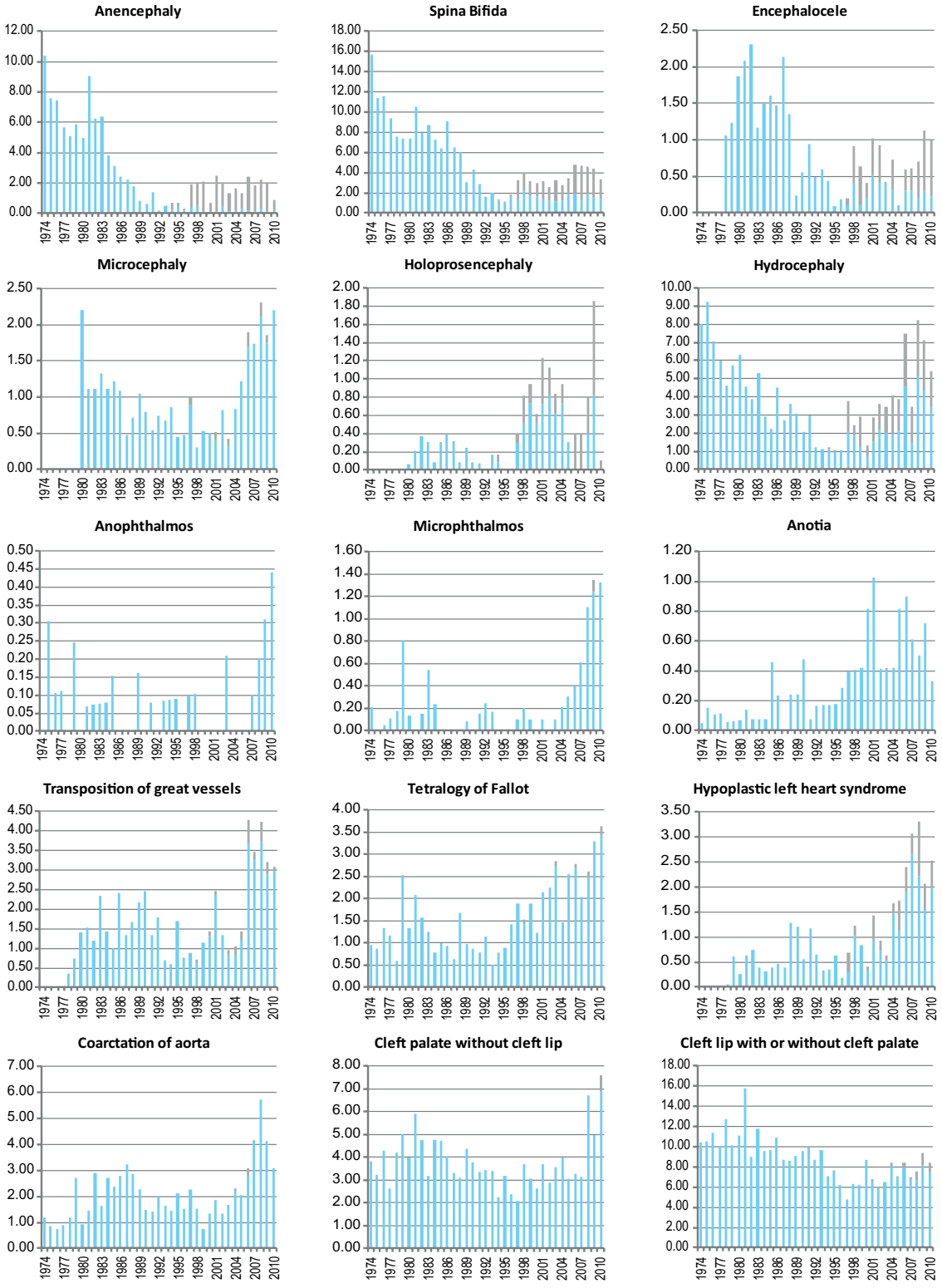
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**1,230,902**	**663,967**	**631,149**	**595,926**	**497,607**	**483,716**	**485,721**
Anencephaly	6.82	5.80	1.57	0.70	1.39	1.78	1.89
Spina bifida	10.23	8.22	5.80	1.81	2.99	3.04	4.39
Encephalocele	1.37*	1.75	1.16	0.52	0.46	0.64	0.80
Microcephaly	2.20*	1.17	0.82	0.65	0.56	0.76	2.00
Holoprosencephaly	0.07*	0.26	0.22	0.08	0.54	0.89	0.72
Hydrocephaly	6.80	3.80	3.18	1.54	2.29	3.58	6.36
Anophthalmos	0.11	0.09	0.03	0.07	0.04	0.04	0.21
Microphthalmos	0.20	0.18	0.02	0.12	0.08	0.14	0.95
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	nr	nr	nr
Anotia	0.09	0.17	0.24	0.15	0.46	0.62	0.62
Microtia	0.05	0.02	0.02	0.03	0.02	0.10	0.14
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.81*	1.49	2.01	1.22	0.98	1.45	3.66
Tetralogy of Fallot	1.23	1.36	1.01	0.82	1.59	2.25	2.86
Hypoplastic left heart syndrome	0.31*	0.50	0.78	0.64	0.66	1.28	2.68
Coarctation of aorta	1.19	2.20	2.54	1.71	1.49	1.84	4.06
Choanal atresia, bilateral	0.33*	0.11	0.11	0.17	0.04	0.04	0.86
Cleft palate without cleft lip	3.85	4.70	3.72	3.14	2.75	3.43	5.11
Cleft lip with or without cleft palate	10.87	11.22	9.38	8.64	6.43	6.95	8.11
Oesophageal atresia/stenosis with or without fistula	1.96*	1.64	1.93	1.11	0.96	1.24	2.43
Small intestine atresia/stenosis	1.33*	1.43	1.28	0.96	0.52	1.03	2.29
Anorectal atresia/stenosis	2.14*	2.26	1.90	1.31	0.88	1.12	2.92
Undescended testis (36 weeks of gestation or later)	15.68*	17.65	16.43	14.83	9.45	14.86	20.86
Hypospadias	16.28	21.19	21.22	21.13	18.99	23.84	28.88
Epispadias	nr	nr	nr	nr	nr	nr	0.28*
Indeterminate sex	0.13*	0.35	0.33	0.17	0.12	0.45	0.47
Renal agenesis	1.41*	0.83	1.20	0.59	0.18	0.48	1.24
Cystic kidney	0.00*	0.05	0.24	0.44	1.63	2.85	4.67
Bladder exstrophy	0.13*	0.42	0.35	0.05	0.08	0.10	0.33
Polydactyly, preaxial	0.00*	1.20	2.11	1.14	6.43	8.15	9.41
Total Limb reduction defects (include unspecified)	nr	4.35*	3.90	2.72	3.22	3.12	3.69
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	1.96	2.35	2.19	1.38	0.84	0.54	2.84
Omphalocele	nr	1.98*	1.14	0.72	0.86	1.16	1.59
Gastroschisis	nr	0.46*	0.52	0.59	0.58	0.79	1.19
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	nr	nr
Prune belly sequence	nr	nr		0.00*	0.10	0.00	0.06
Trisomy 13	nr	0.17*	0.24	0.20	0.26	0.76	1.32
Trisomy 18	nr	0.25*	0.30	0.22	0.72	1.72	3.05
Down syndrome, all ages (include age unknown)	8.98	8.03	8.32	8.16	8.32	14.06	18.61
<20	nr	1.80*	1.97	1.64	2.77	6.52	8.11
20-24	nr	2.11*	2.88	2.06	3.58	7.47	6.77
25-29	nr	3.54*	4.28	2.75	4.42	7.99	8.27
30-34	nr	5.02*	5.50	4.52	6.71	13.93	13.63
35-39	nr	11.82*	17.97	18.28	21.12	41.01	50.71
40-44	nr	57.92*	57.61	78.04	106.78	164.09	148.57
45+	nr	nr	nr	nr	nr	nr	334.73*
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 7 or 5 years

Hungary

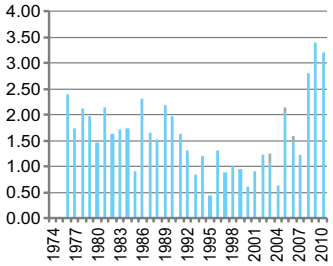
Time trends 1974-2010 (Birth prevalence rates per 10,000)



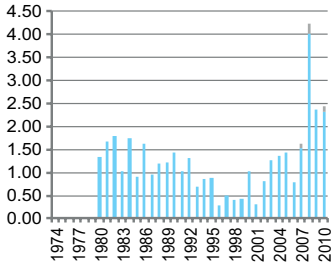
Note: L+S rates, ToP rates

Hungary

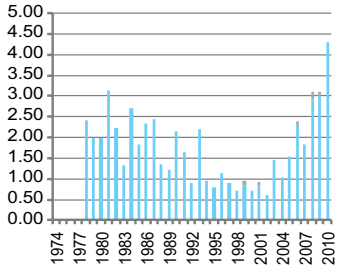
Oesophageal atresia/stenosis with or without fistula



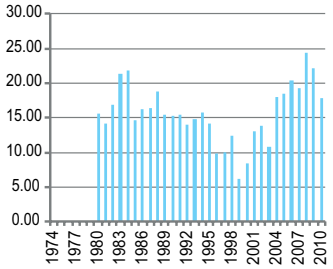
Small intestine atresia/stenosis



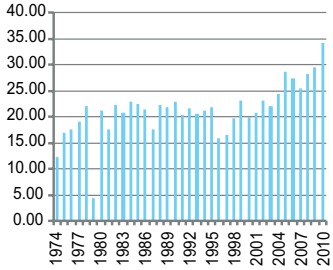
Anorectal atresia/stenosis



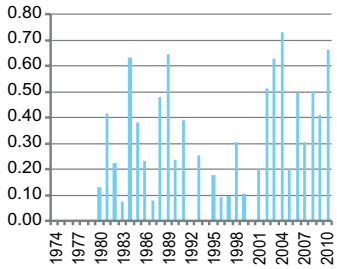
Undescended testis



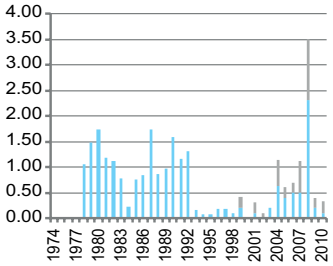
Hypospadias



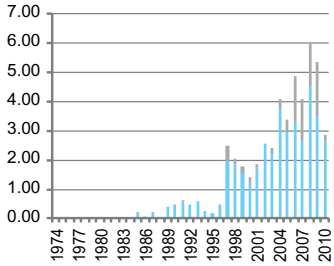
Indeterminate sex



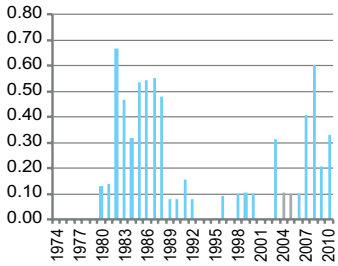
Renal agenesis



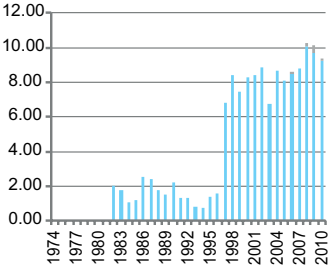
Cystic kidney



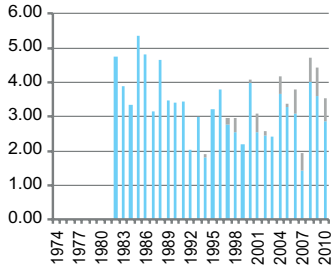
Bladder exstrophy



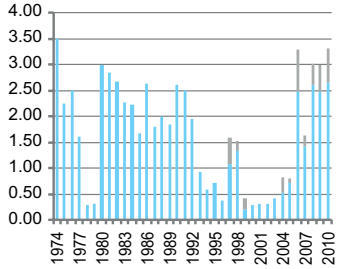
Polydactyly, preaxial



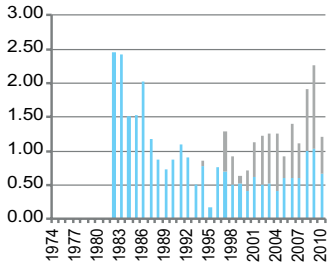
Limb reduction defects



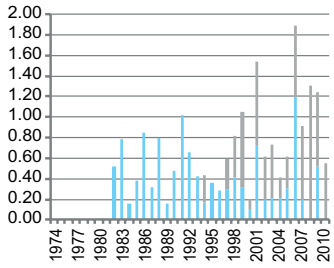
Diaphragmatic hernia



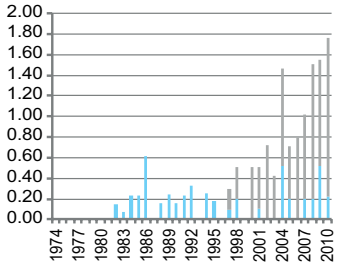
Omphalocele



Gastroschisis

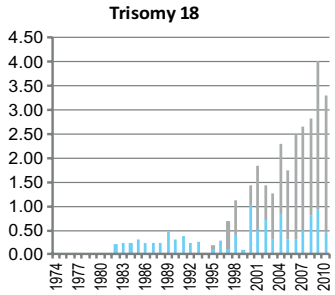


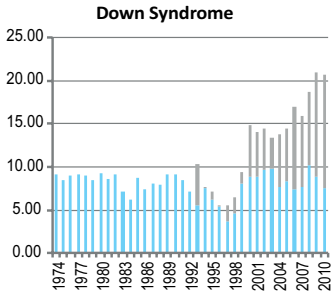
Trisomy 13

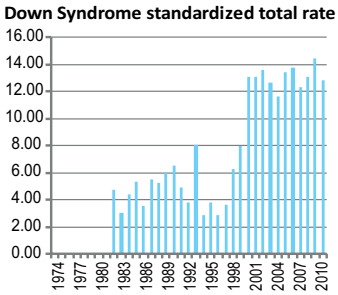


Note: L+S rates, ToP rates

Hungary







Note: L+S rates, ToP rates

India: BDRI
Birth Defects Registry of India

History:
BDRI is a part of Fetal Care Research Association a not for profit organisation that is dedicated to Preventive Curative and Supportive care of Birth Defects. With a population of 1.21 billion India is second only to China in population. Every year, India adds more people than any other nation in the world, and in fact the individual population of some of its states is equal to the total population of many countries. Founded in 2001, BDRI started with a few chennai hospitals and reported 15000 births. Initially BDRI encouraged each district to have a nodal leader which in turn would collect data from participant hospitals and submit it to the Central Registry. The data was sent as hard copy files by post. But in time it was found that there was more reception to the idea of individual reporting and therefore we now have around 750 hospitals reporting data from all over India across 28 states and three union territories. The Registry now has the facilty of online reporting which has made it user friendly. BDRI has so far analysed almost 10 lakh births . As a result of these studies important conclusions have been made on birth defects in general and neural tube defects in particular. In return to the member hospitals who contribute data, BDRI shares its study in the form of quarterly meetings and quarterly newsletters, thereby helping in evolving strategies on handling birth defects.Out of a total of birth of 25 million a year BDRI represents only an annual birth of 2 lakhs a year as it is a voluntary hospital based passive Registry. Statistical Report is published annually.

Legislation and funding:
The funding is by Fetal Care Research Foundation and we do not have any external funding. But however as a fallout of this program the Government collaborated with us for Project on NTD.

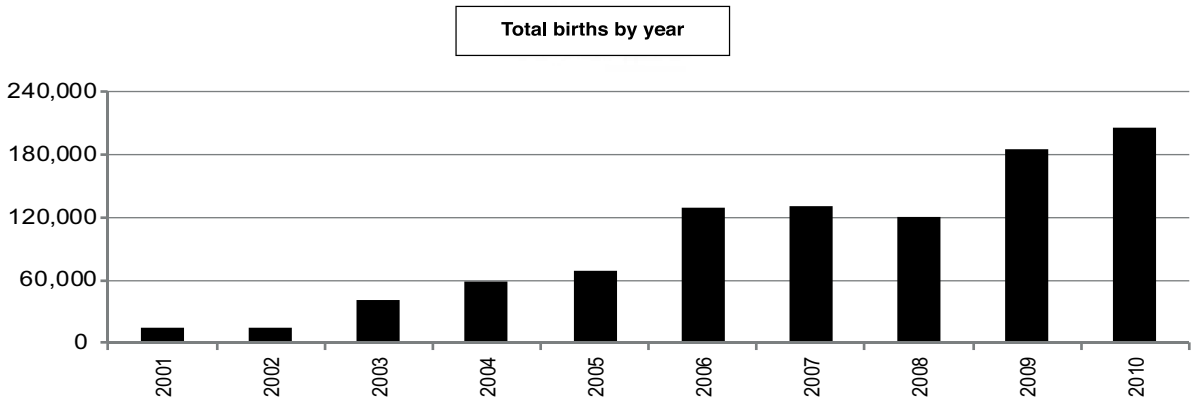
Sources of ascertainment:
All our contributing hospitals are Obstetrics hospitals and the idea of Paediatricians and neonatologists contributing is just picking up.

Exposure information:
We do not have any exposure information.

Background information:
BDRI is a hospital based passive registry.
The inclusion criteria is for both major and minor anomalies diagnosed in the antenatal period up to children of one year of age.The exclusion criteria is for Functional problems without any obvious structural anomaly; e.g. murmur with no structural abnormalities in the heart & Hydrops due to Rh iso immunisation or unknown etiology, IUGR due to placental causes & Preterm births

Addresses and Staff:
Dr Prof S.Suresh From 2001 (inception) till date.
Director, Birth Defects Registry Of India
Managing Director, MediScan Systems
197, Dr Natesan Road
Mylapore, Chennai – 4
India
E-mail: mediscan@gmail.com
Website: www.mediscansystems.org.in

India: BDRI



Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	303	51.1	Cystic kidney	53	34.4
Spina bifida	235	36.2	Limb reduction defects	24	16.3
Encephalocele	54	50.5	Diaphragmatic hernia	37	24.5
Holoprosencephaly	33	57.9	Omphalocele	55	44.7
Hydrocephaly	138	28.3	Gastroschisis	22	48.9
Hypoplastic left heart syndrome	30	56.6	Trisomy 13	3	60.0
Cleft palate without cleft lip	7	8.3	Trisomy 18	4	36.4
Cleft lip with or without cleft palate	34	15.8	Down syndrome	18	34.6
Renal agenesis	29	46.0			

Total ToPs with births defects = 1,262 (Ratio ToPs/Births: 2,47 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

India: BDRI, 2010

Live births (LB)	199,687
Stillbirths (SB)	5,598
Total births	205,285
Number of terminations of pregnancy (ToP) for birth defects	494

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	14	83	119	10.52
Spina bifida	63	76	86	10.96
Encephalocele	6	9	17	1.56
Microcephaly	18	7	1	1.27
Holoprosencephaly	5	6	20	1.51
Hydrocephaly	61	56	55	8.38
Anophthalmos	2	0	0	0.10
Microphthalmos	4	2	1	0.34
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	1	0	0.10
Microtia	7	0	0	0.34
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	3	0	5	0.39
Tetralogy of Fallot	3	3	4	0.49
Hypoplastic left heart syndrome	6	1	14	1.02
Coarctation of aorta	3	0	0	0.15
Choanal atresia, bilateral	2	0	0	0.10
Cleft palate without cleft lip	28	6	4	1.85
Cleft lip with or without cleft palate	37	5	3	2.19
Oesophageal atresia/stenosis with or without fistula	24	3	4	1.51
Small intestine atresia/stenosis	8	3	2	0.63
Anorectal atresia/stenosis	29	5	1	1.70
Undescended testis (36 weeks of gestation or later)	11	2	1	0.68
Hypospadias	30	0	1	1.51
Epispadias	0	0	0	0.00
Indeterminate sex	7	6	2	0.73
Renal agenesis	5	1	10	0.78
Cystic kidney	17	17	23	2.78
Bladder exstrophy	6	4	6	0.78
Polydactyly, preaxial	38	7	10	2.68
Total Limb reduction defects (include unspecified)	27	17	12	2.73
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	40	9	15	3.12
Omphalocele	6	10	19	1.70
Gastroschisis	4	3	7	0.68
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	2	1	2	0.24
Trisomy 13	1	1	1	0.15
Trisomy 18	0	2	0	0.10
Down syndrome, all ages (include age unknown)	8	2	6	0.78
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported

India: BDRI, Previous years rates 2001 - 2010

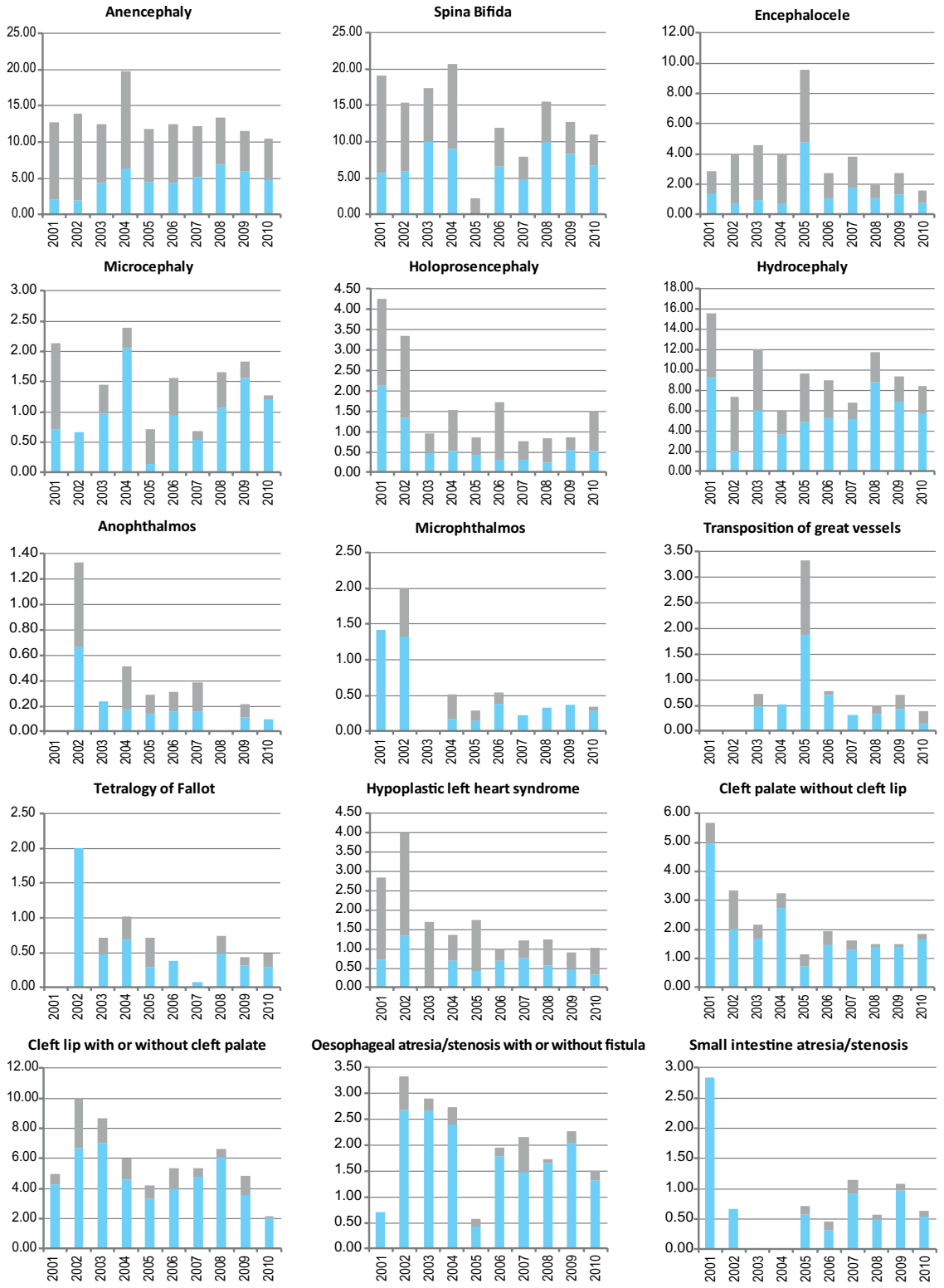
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births						**198,372**	**770,834**
Anencephaly						14.57	11.83
Spina bifida						13.06	11.78
Encephalocele						5.95	2.49
Microcephaly						1.46	1.41
Holoprosencephaly						1.51	1.15
Hydrocephaly						9.33	8.98
Anophthalmos						0.40	0.19
Microphthalmos						0.50	0.36
Unspecified Anophthalmos/Microphthalmos						0.00	0.01
Anotia						0.00	0.08
Microtia						0.05	0.14
Unspecified Anotia/Microtia						0.00	0.00
Transposition of great vessels						1.46	0.53
Tetralogy of Fallot						0.86	0.43
Hypoplastic left heart syndrome						1.87	1.06
Coarctation of aorta						0.81	0.10
Choanal atresia, bilateral						0.25	0.04
Cleft palate without cleft lip						2.47	1.69
Cleft lip with or without cleft palate						6.15	4.59
Oesophageal atresia/stenosis with or without fistula						1.92	1.91
Small intestine atresia/stenosis						0.50	0.79
Anorectal atresia/stenosis						0.71	1.93
Undescended testis (36 weeks of gestation or later)						1.11	0.99
Hypospadias						2.32	1.82
Epispadias						0.00	0.01
Indeterminate sex						2.82	1.34
Renal agenesis						3.02	1.47
Cystic kidney						4.84	2.93
Bladder exstrophy						0.81	0.49
Polydactyly, preaxial						3.08	3.23
Total Limb reduction defects (include unspecified)						7.86	4.22
Transverse						nr	nr
Preaxial						nr	nr
Postaxial						nr	nr
Intercalary						nr	nr
Mixed						nr	nr
Unspecified						nr	nr
Diaphragmatic hernia						3.53	2.74
Omphalocele						3.02	2.31
Gastroschisis						0.76	0.75
Unspecified Omphalocele/Gastroschisis						0.00	0.09
Prune belly sequence						0.15	0.23
Trisomy 13						0.25	0.06
Trisomy 18						0.50	0.30
Down syndrome, all ages (include age unknown)						1.31	0.92
<20						nr	nr
20-24						nr	nr
25-29						nr	nr
30-34						nr	nr
35-39						nr	nr
40-44						nr	nr
45+						nr	nr
unknown						---	---

nr = not reported

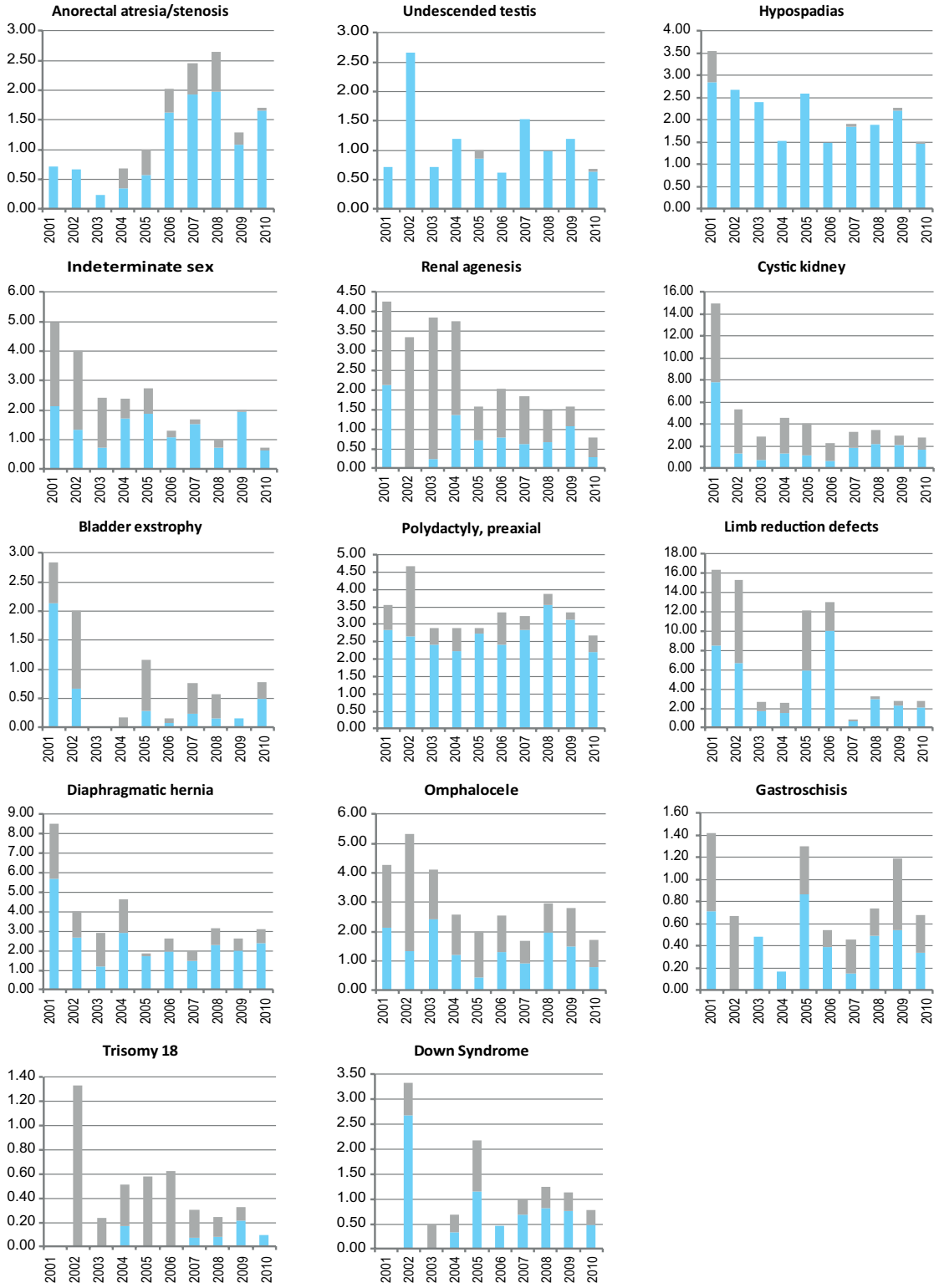
India: BDRI

Time trends 2001-2010 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

India: BDRI



Note: L+S rates, ToP rates

Iran: TRoCA
Tabriz Registry of Congenital Anomalies

History:
The programme was initiated in 2000, but the registry started in 2003. It was then accepted as a member of the ICBDSR in the 2006 annual meeting in Uppsala, Sweden. Since 2012, the registry is also a "World Affiliate" member of the European network of registries for the epidemiologic surveillance of congenital anomalies (EUROCAT).

Size and coverage:
TROCA is a hospital-based registry and situated in the northwest of Iran covering all births and children in three university hospitals in the city of Tabriz. This city is one of the three major cities in the country. The programme is based on approximately 60-70% of all births (20000 births per year) in the area.

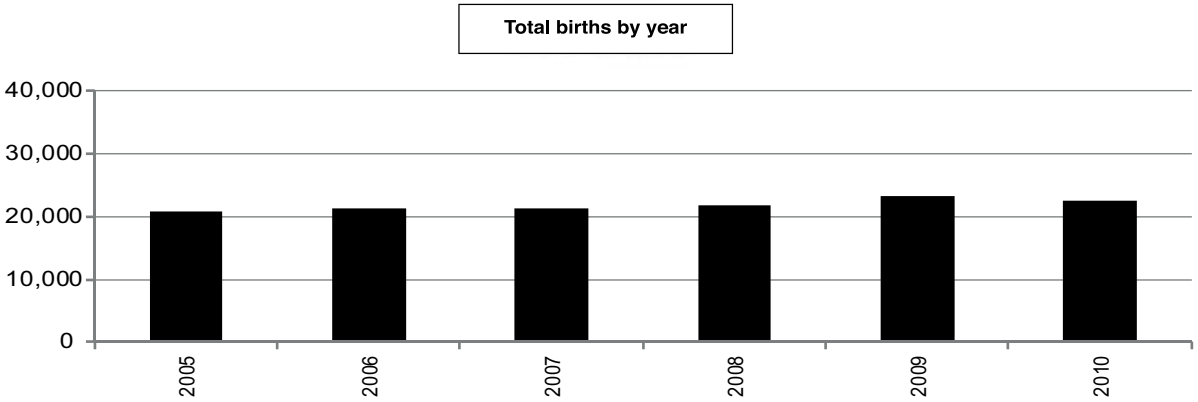
Legislation and funding:
The programme has been financially supported by the National Public Health Management Centre (a WHO collaborating centre) in Tabriz University of Medical Sciences.

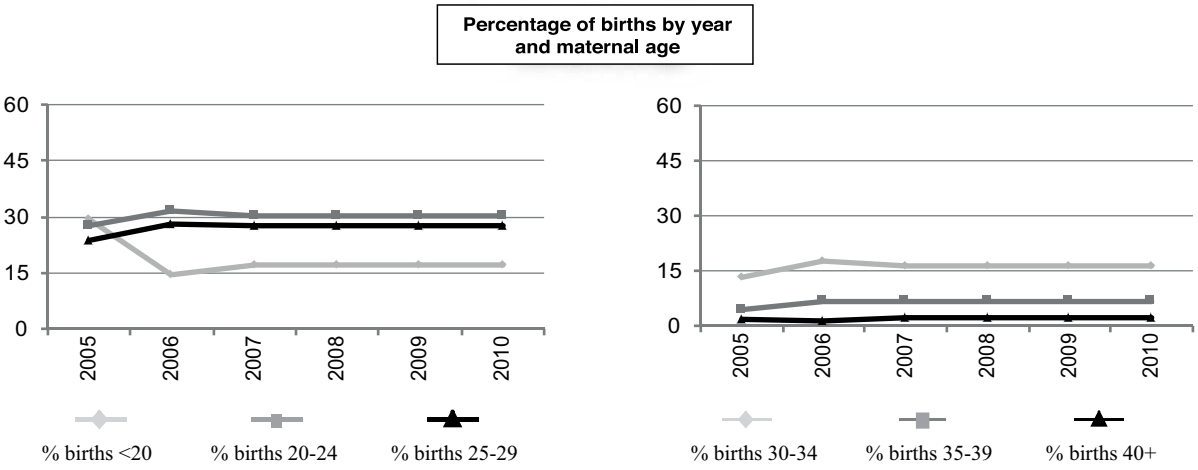
Exposure information:
Some exposure information is currently available of mothers of all malformed infants. Other women giving births in all university hospitals with normal newborns routinely complete a similar form. They might be considered as matched control group.

Background information:
General epidemiological data and basic characteristic information are available for all births.

Addresses and Staff:
Dr. Saeed Dastgiri,
Programme Director
Department of Community and Family Medicine
School of Medicine
Tabriz University of Medical Sciences
Tabriz, Iran
Phone: 98-914 415 7039
Fax: 98-411 336 4668
E-mail: saeed.dastgiri@gmail.com
Website: http://troca.tbzmed.ac.ir

Iran: TRoCA


Total births by year
40,000
30,000
20,000
10,000
0
2005
2006
2007
2008
2009
2010


Percentage of births by year and maternal age
60
45
30
15
0
2005
2006
2007
2008
2009
2010
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Iran:TRoCA, 2010

Live births (LB)	23,320
Stillbirths (SB)	204
Total births	22,524
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	8	6	nr	6.22
Spina bifida	4	nr	nr	1.78
Encephalocele	nr	nr	nr	nr
Microcephaly	6	nr	nr	2.66
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	13	2	nr	6.66
Anophthalmos	nr	nr	nr	nr
Microphthalmos	4	nr	nr	1.78
Unspecified Anophthalmos/Microphthalmos	9	nr	nr	4.00
Anotia nr	nr	nr	nr	
Microtia	7	nr	nr	3.11
Unspecified Anotia/Microtia	25	2	nr	11.99
Transposition of great vessels	nr	nr	nr	nr
Tetralogy of Fallot	5	nr	nr	2.22
Hypoplastic left heart syndrome	10	nr	nr	4.44
Coarctation of aorta	4	nr	nr	1.78
Choanal atresia, bilateral	nr	nr	nr	nr
Cleft palate without cleft lip	34	nr	nr	15.10
Cleft lip with or without cleft palate	47	nr	nr	20.87
Oesophageal atresia/stenosis with or without fistula	37	nr	nr	16.43
Small intestine atresia/stenosis	28	nr	nr	12.43
Anorectal atresia/stenosis	41	nr	nr	18.20
Undescended testis (36 weeks of gestation or later)	37	nr	nr	16.43
Hypospadias	55	nr	nr	24.42
Epispadias	1	nr	nr	0.44
Indeterminate sex	2	2	nr	1.78
Renal agenesis	4	nr	nr	1.78
Cystic kidney	3	nr	nr	1.33
Bladder exstrophy	nr	nr	nr	nr
Polydactyly, preaxial	29	nr	nr	12.88
Total Limb reduction defects (include unspecified)	180	nr	nr	79.91
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	19	nr	nr	8.44
Omphalocele	8	nr	nr	3.55
Gastroschisis	nr	2	nr	0.89
Unspecified Omphalocele/Gastroschisis	15	nr	nr	6.66
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	2	nr	nr	0.89
Trisomy 18	nr	nr	nr	nr
Down syndrome, all ages (include age unknown)	42	2	nr	19.53
<20	4	0	nr	10.49
20-24	5	0	nr	7.33
25-29	20	0	nr	32.37
30-34	9	0	nr	24.18
35-39	0	0	nr	0.00
40-44	4	2	nr	155.44
45+	0	0	nr	0.00
unknown	0	0	nr	---

nr = not reported

Iran:TRoCA, Previous years rates 2005 - 2010

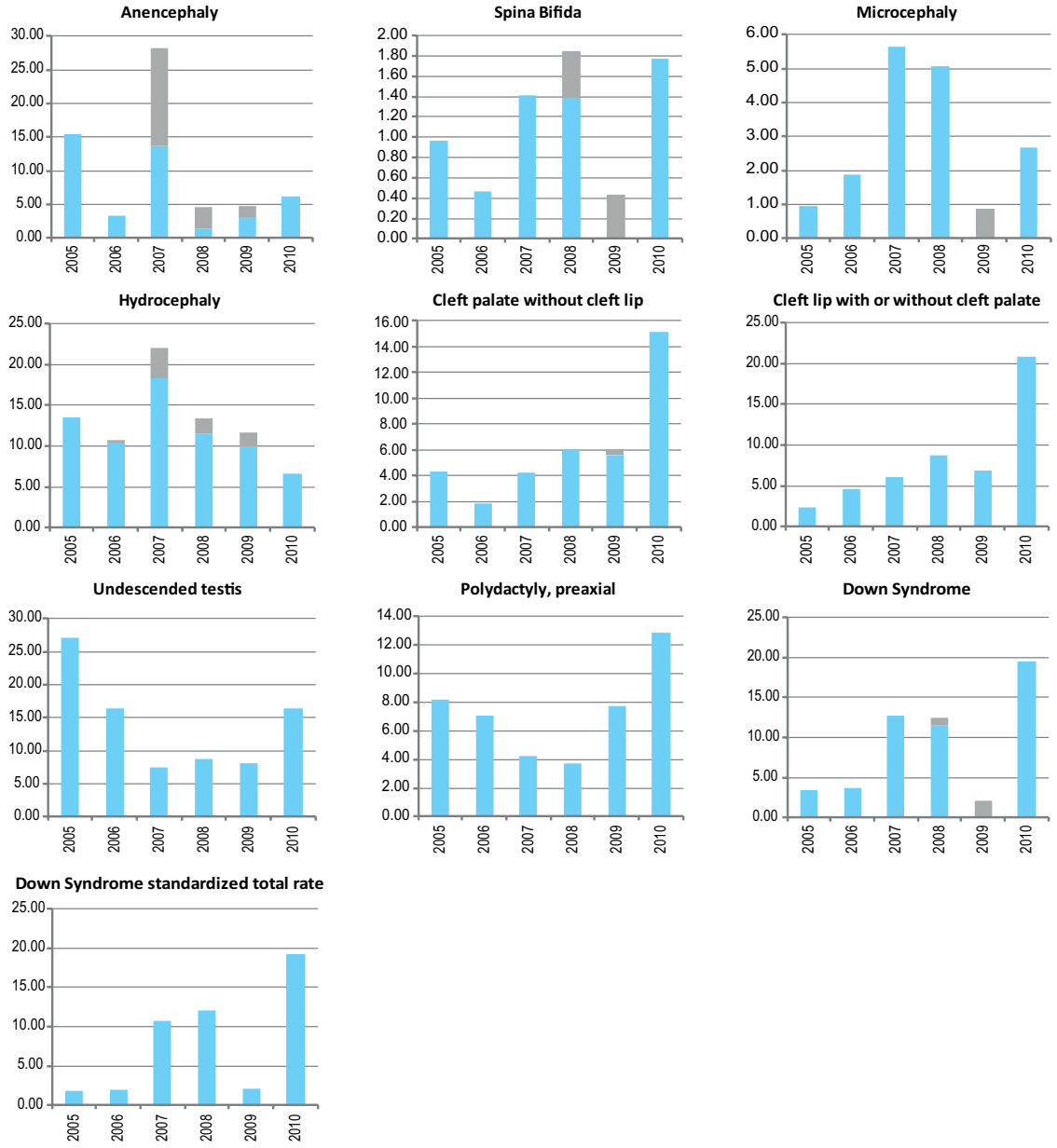
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005*	2006-2010
Total births						**20,702**	**110,022**
Anencephaly						15.46	9.27
Spina bifida						0.97	1.18
Encephalocele						0.48	1.51*
Microcephaly						0.97	3.18
Holoprosencephaly						nr	nr
Hydrocephaly						13.53	12.82
Anophthalmos						nr	0.47*
Microphthalmos						0.48	1.07*
Unspecified Anophthalmos/Microphthalmos						0.48	2.46*
Anotia						nr	nr
Microtia						nr	1.81*
Unspecified Anotia/Microtia						nr	5.03*
Transposition of great vessels						0.48	5.75*
Tetralogy of Fallot						nr	1.07*
Hypoplastic left heart syndrome						nr	3.84*
Coarctation of aorta						nr	1.77*
Choanal atresia, bilateral						nr	nr
Cleft palate without cleft lip						4.35	6.73
Cleft lip with or without cleft palate						2.42	10.25*
Oesophageal atresia/stenosis with or without fistula						1.93	14.40*
Small intestine atresia/stenosis						nr	11.99*
Anorectal atresia/stenosis						1.45	8.29+
Undescended testis (36 weeks of gestation or later)						27.05	12.32*
Hypospadias						6.76	15.09*
Epispadias						nr	0.68*
Indeterminate sex						nr	1.78*
Renal agenesis						0.97	1.37*
Cystic kidney						nr	1.22*
Bladder exstrophy						nr	nr
Polydactyly, preaxial						8.21	7.02*
Total Limb reduction defects (include unspecified)						20.29	44.99*
Transverse						nr	nr
Preaxial						nr	nr
Postaxial						nr	nr
Intercalary						nr	nr
Mixed						nr	nr
Unspecified						20.29	nr
Diaphragmatic hernia						nr	5.76*
Omphalocele						0.48	1.64*
Gastroschisis						nr	nr
Unspecified Omphalocele/Gastroschisis						nr	2.67*
Prune belly sequence						nr	nr
Trisomy 13						nr	1.13*
Trisomy 18						0.97	0.78*
Down syndrome, all ages (include age unknown)						3.38	10.09
<20						0.00	6.08
20-24						1.75	5.96*
25-29						0.00	17.82*
30-34						3.68	9.22
35-39						10.67	17.68
40-44						0.00	66.45
45+						0.00	95.69*
unknown						---	---

nr = not reported
* data include less than 5 years

Iran: TRoCA

Time trends 2001-2010 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

Ireland
Dublin EUROCAT Registry

History:
Register began in September 1979 and joined EUROCAT at the same time. Joined International Clearinghouse in 1997.

Size and coverage:
The Registry is population-based and situated in the East of Ireland covering the counties of Dublin, Wicklow and Kildare. About one third (25,000 births) of all births in Ireland occur in this region.

Legislation and funding:
The Registry is located within Health Intelligence in the Health Service Executive in Dublin. Staffing includes a full time nurse/researcher and a part-time public health specialist. Funding is provided by the Department of Health through the Health Service Executive. The registry is one of three congenital anomaly registers in Ireland. There is a National Steering Committee for the three registries, it is comprised of specialists from maternity and paediatric Hospitals, the Department of Health & Children and the National Perinatal Epidemiological Centre.

Exposure information:
For each malformed infant reported, limited information is given on certain exposures. No information is available on controls.

Sources of ascertainment:
All live and still births included. Termination of pregnancy is not legal in Ireland.

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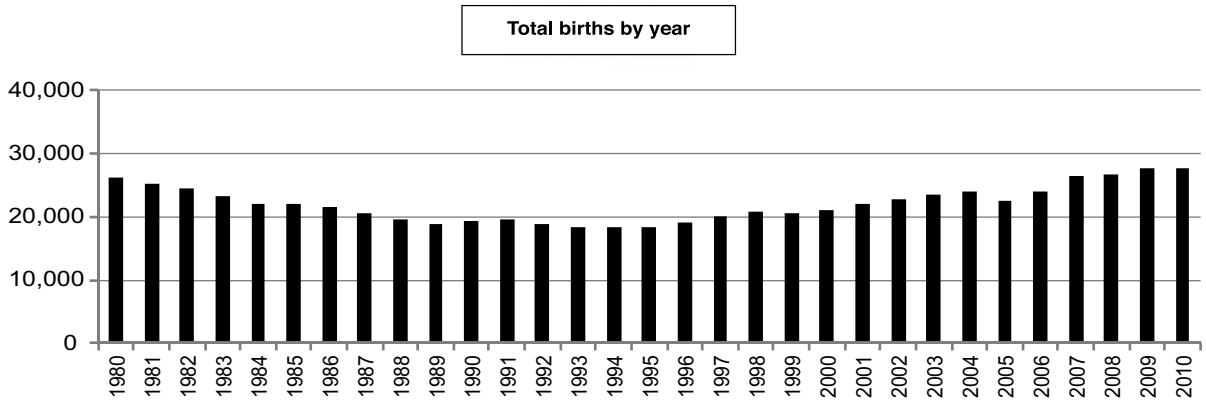
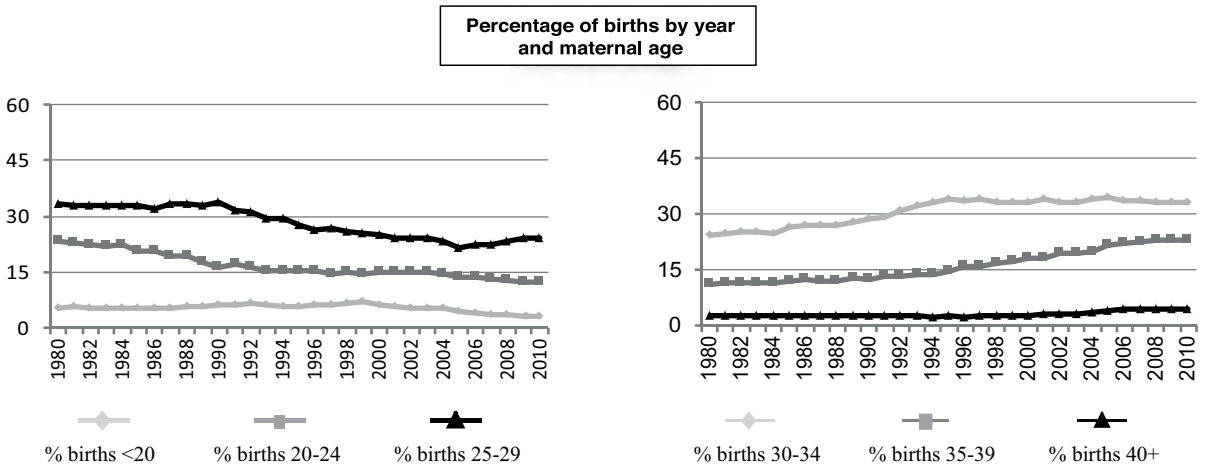




Ireland: Dublin, 2010

Live births (LB)	27,515
Stillbirths (SB)	120
Total births	27,635
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	0		1.09
Spina bifida	8	0		2.89
Encephalocele	1	0		0.36
Microcephaly	2	0		0.72
Holoprosencephaly	0	3		1.09
Hydrocephaly	4	1		1.81
Anophthalmos	0	0		0.00
Microphthalmos	0	0		0.00
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	0	0		0.00
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	12	0		4.34
Tetralogy of Fallot	8	0		2.89
Hypoplastic left heart syndrome	5	1		2.17
Coarctation of aorta	9	1		3.62
Choanal atresia, bilateral	2	0		0.72
Cleft palate without cleft lip	19	1		7.24
Cleft lip with or without cleft palate	17	1		6.51
Oesophageal atresia/stenosis with or without fistula	8	0		2.89
Small intestine atresia/stenosis	1	0		0.36
Anorectal atresia/stenosis	6	1		2.53
Undescended testis (36 weeks of gestation or later)	0	0		0.00
Hypospadias	23	1		8.68
Epispadias	nr	nr		nr
Indeterminate sex	0	0		0.00
Renal agenesis	3	3		2.17
Cystic kidney	8	0		2.89
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	13	0		4.70
Total Limb reduction defects (include unspecified)	5	0		1.81
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	nr	nr		nr
Diaphragmatic hernia	6	1		2.53
Omphalocele	5	2		2.53
Gastroschisis	3	0		1.09
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	2		1.09
Trisomy 18	2	7		3.26
Down syndrome, all ages (include age unknown)	45	6		18.45
<20	1	1		23.45
20-24	3	0		8.94
25-29	5	0		7.59
30-34	9	1		10.94
35-39	20	3		36.15
40-44	7	1		69.63
45+	0	0		0.00
unknown	0	0		---

nr = not reported
Births by maternal age for 2010 are estimated

Ireland: Dublin, Previous years rates 1980 - 2010

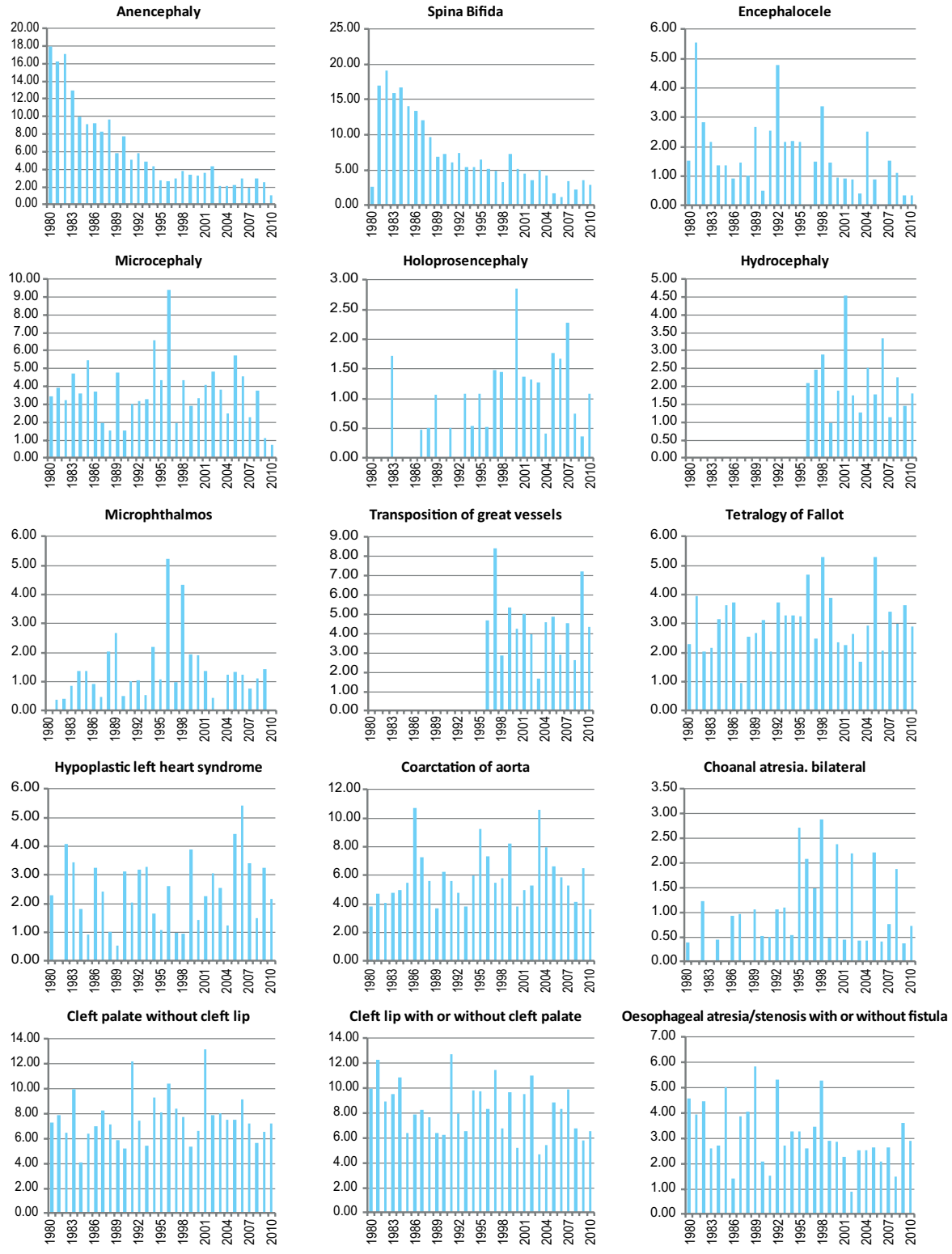
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**26,202**	**117,167**	**99,902**	**93,658**	**101,861**	**114,980**	**132,253**
Anencephaly	17.94	13.23	8.21	4.59	3.24	2.87	2.27
Spina bifida	2.67	16.64	10.01	6.19	5.20	3.83	2.72
Encephalocele	1.53	2.73	1.30	2.78	1.47	1.13	0.68
Microcephaly	3.43	4.18	2.70	4.06	4.32	4.17	2.42
Holoprosencephaly	0.00	0.34	0.40	0.64	1.28	1.22	1.21
Hydrocephaly	nr	nr	nr	nr	2.06	2.35	1.97
Anophthalmos	0.00	0.34	0.00	0.43	0.59	0.17	0.30
Microphthalmos	0.00	0.85	1.30	1.17	2.85	0.87	0.91
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.10	0.09	0.00
Anotia	nr	nr	nr	nr	nr	0.11*	0.23
Microtia	nr	nr	nr	nr	nr	0.11*	0.08
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	0.00*	0.00
Transposition of great vessels	nr	nr	nr	nr	5.10	4.00	4.39
Tetralogy of Fallot	2.29	2.99	2.60	3.10	3.73	2.96	3.02
Hypoplastic left heart syndrome	2.29	2.05	2.10	2.24	1.96	2.70	3.10
Coarctation of aorta	3.82	4.78	6.81	5.87	6.09	7.13	5.07
Choanal atresia, bilateral	0.38	0.34	0.70	1.17	1.87	1.13	0.83
Cleft palate without cleft lip	7.25	7.00	6.71	8.54	7.66	8.78	7.11
Cleft lip with or without cleft palate	9.92	9.64	7.31	9.40	8.25	7.83	7.41
Oesophageal atresia/stenosis with or without fistula	4.58	3.76	3.40	3.20	3.44	2.17	2.57
Small intestine atresia/stenosis	2.29	2.90	2.70	2.03	2.26	0.87	0.98
Anorectal atresia/stenosis	2.67	3.41	4.30	2.88	2.06	3.04	3.33
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	0.00*
Hypospadias	12.21	15.28	10.61	12.71	18.85	12.87	9.83
Epispadias	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	0.00	0.17	0.30	0.11	0.39	0.35	0.38
Renal agenesis	5.34	5.29	3.70	4.06	4.81	1.65	1.89
Cystic kidney	1.14	4.01	1.80	4.59	3.34	3.83	4.01
Bladder exstrophy	nr	nr	nr	nr	0.00	1.04	0.45
Polydactyly, preaxial	8.01	6.66	4.90	5.66	7.56	9.83	8.09
Total Limb reduction defects (include unspecified)	4.58	3.84	4.20	3.95	4.61	4.17	3.40
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	3.05	3.24	4.20	4.80	4.42	3.48	3.18
Omphalocele	2.29	2.56	2.60	2.14	2.65	3.74	2.19
Gastroschisis	0.00	0.34	0.40	1.17	2.65	3.04	2.04
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Prune belly sequence	0.00	0.09	0.50	0.53	0.39	0.70	0.30
Trisomy 13	1.14	1.02	1.20	0.64	3.44	2.17	1.74
Trisomy 18	1.91	2.30	2.00	3.20	4.12	4.26	4.08
Down syndrome, all ages (include age unknown)	21.75	18.44	17.92	20.93	23.27	20.96	23.29
<20	nr	nr	nr	17.96*	7.57	8.37	8.85
20-24	nr	nr	nr	7.84*	7.89	7.83	9.00
25-29	nr	nr	nr	9.68*	10.30	5.96	9.45
30-34	nr	nr	nr	17.85*	18.25	13.74	18.41
35-39	nr	nr	nr	42.21*	51.61	45.21	43.30
40-44	nr	nr	nr	164.38*	144.81	132.28	84.45
45+	nr	nr	nr	869.56*	560.75	180.18	0.00
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 7 or 5 years

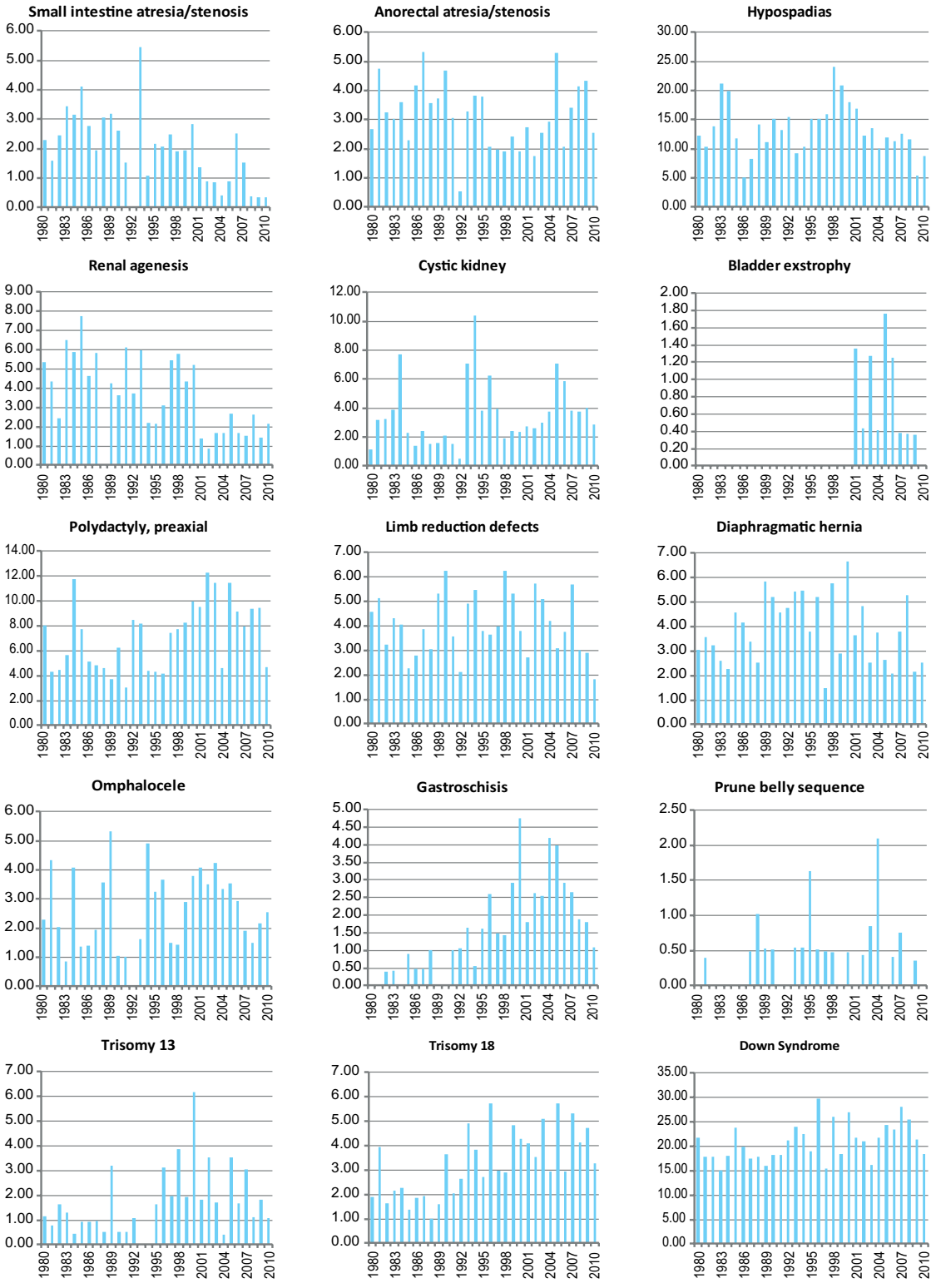
Ireland: Dublin

Time trends 1980-2010 (Birth prevalence rates per 10,000)



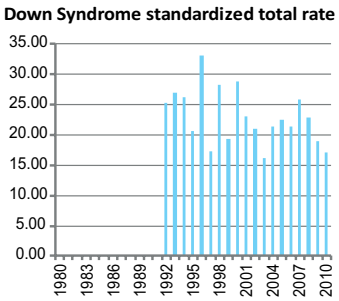
Note: L+S rates

Ireland: Dublin



Note: L+S rates

Ireland: Dublin



Note: L+S rates

Israel: IBDSP

Israel Birth Defects Surveillance Program

History :
the Programme started in one hospital in 1966 and was a founding member of Clearinghouse.

Size and coverage:
Reports are now obtained from five hospitals located in all regions of the country, with more than 40,000 births per year (about 25% of all annual births in Israel). Stillbirths of 20 weeks gestation or more and 500g or more are included. The registry of termination of pregnancy began in 1995.

Legislation and funding :
The Programme is a research and surveillance one supported by the Directors of the Departments of Neonatology and by research grants without any governmental support.

Sources of ascertainment :
Reporting is voluntary. Reports are obtained from Delivery units and Departments of Neonatology in the participating hospitals. The five included hospitals are:
Rabin Medical Center, Beilinson and Schneider Hospitals, Petah Tikva (Prof L.Sirota , Prof N. Linder); Kaplan Hospital, Rehovot (Prof E. Shinwell); Lis Medical Center, Tel-Aviv (Prof Dohlberg). These hospitals are affiliated to Sackler School of Medicine, Tel-Aviv University.
Soroka Medical Center, Beer-Sheva (Prof E. Zmora, Dr D. Landau) affiliated to Ben-Gurion University of Negev; Bnai-Zion Medical Center, Haifa (Prof. D. Bader, Dr M Grun) affiliated to the Technion University, Haifa.

Exposure information :
Completeness is obtained by interviews of mothers of all malformed infants. All the other women with normal newborns complete a similar form at birth.

Background information:
Epidemiological information on all births occurring in the participating hospitals is available.

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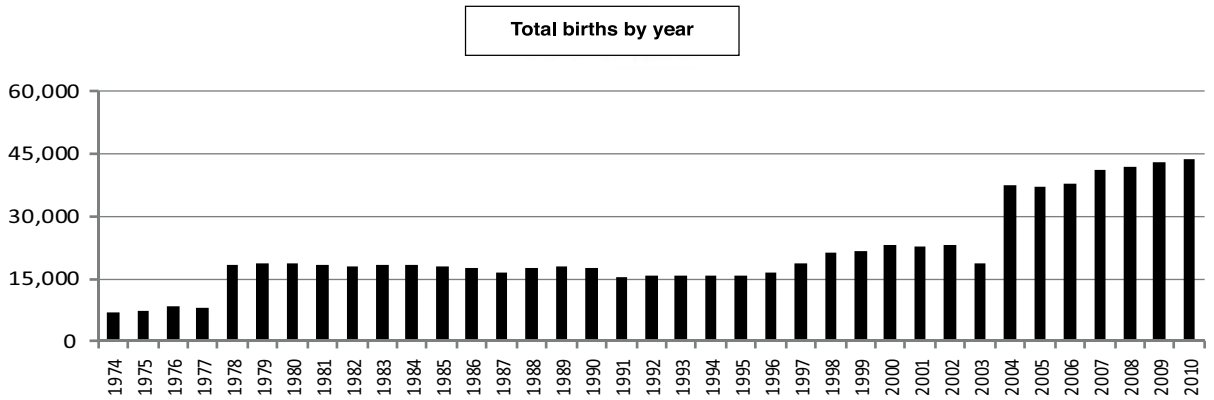
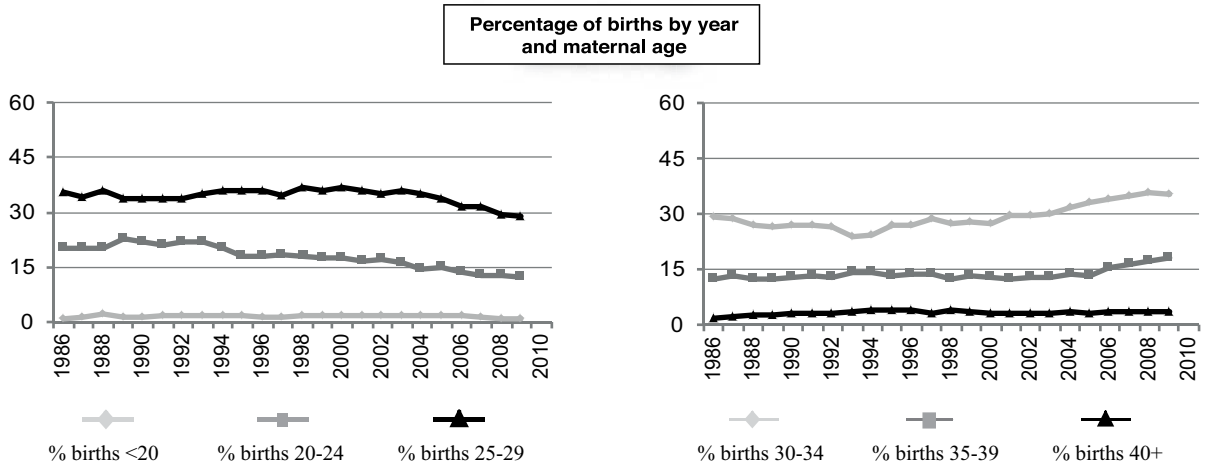
Israel: IBDSP





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	2	13.3	Cystic kidney	0	0.0
Spina bifida	7	15.2	Limb reduction defects	1	4.5
Encephalocele	1	20.0	Diaphragmatic hernia	1	3.8
Holoprosencephaly	2	40.0	Omphalocele	0	0.0
Hydrocephaly	9	18.4	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	1	3.4	Trisomy 13	0	0.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	1	12.5
Cleft lip with or without cleft palate	4	8.5	Down syndrome	13	12.3
Renal agenesis	0	0.0			

Total ToPs with births defects = 32 (Ratio ToPs/Births: 0.25 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Israel: IBDSP, 2010

Live births (LB)	43,506
Stillbirths (SB)	265
Total births	43,771
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	2	1	0.91
Spina bifida	7	7	2	3.66
Encephalocele	0	0	nr	0.00
Microcephaly	7	2	nr	2.06
Holoprosencephaly	1	0	nr	0.23
Hydrocephaly	10	0	4	3.20
Anophthalmos	0	0	nr	0.00
Microphthalmos	0	0	nr	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	3	0	nr	0.69
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	15	0	1	3.66
Tetralogy of Fallot	21	0	nr	4.80
Hypoplastic left heart syndrome	14	0	nr	3.20
Coarctation of aorta	17	0	nr	3.88
Choanal atresia, bilateral	1	0	nr	0.23
Cleft palate without cleft lip	25	1	nr	5.94
Cleft lip with or without cleft palate	16	0	nr	3.66
Oesophageal atresia/stenosis with or without fistula	12	1	nr	2.97
Small intestine atresia/stenosis	2	0	nr	0.46
Anorectal atresia/stenosis	12	0	nr	2.74
Undescended testis (36 weeks of gestation or later)	0	0	nr	0.00
Hypospadias	175	0	nr	39.98
Epispadias	0	0	nr	0.00
Indeterminate sex	3	0	nr	0.69
Renal agenesis	5	0	nr	1.14
Cystic kidney	9	0	nr	2.06
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	5	0	nr	1.14
Total Limb reduction defects (include unspecified)	9	2	nr	2.51
Transverse	5	1	nr	nr
Preaxial	0	0	nr	nr
Postaxial	3	0	nr	nr
Intercalary	0	0	nr	nr
Mixed	0	0	nr	nr
Unspecified	1	1	nr	nr
Diaphragmatic hernia	12	0	1	2.97
Omphalocele	1	0	nr	0.23
Gastroschisis	0	0	nr	0.00
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13	0	0	nr	0.00
Trisomy 18	3	0	nr	0.69
Down syndrome, all ages (include age unknown)	35	0	3	8.68
<20	0	0	nr	nr
20-24	2	0	1	nr
25-29	2	0	nr	nr
30-34	6	0	nr	nr
35-39	12	0	1	nr
40-44	12	0	1	nr
45+	1	0	nr	nr
unknown	0	0	nr	---

nr = not reported

Israel: IBDSP, Previous years rates 1974 - 2010

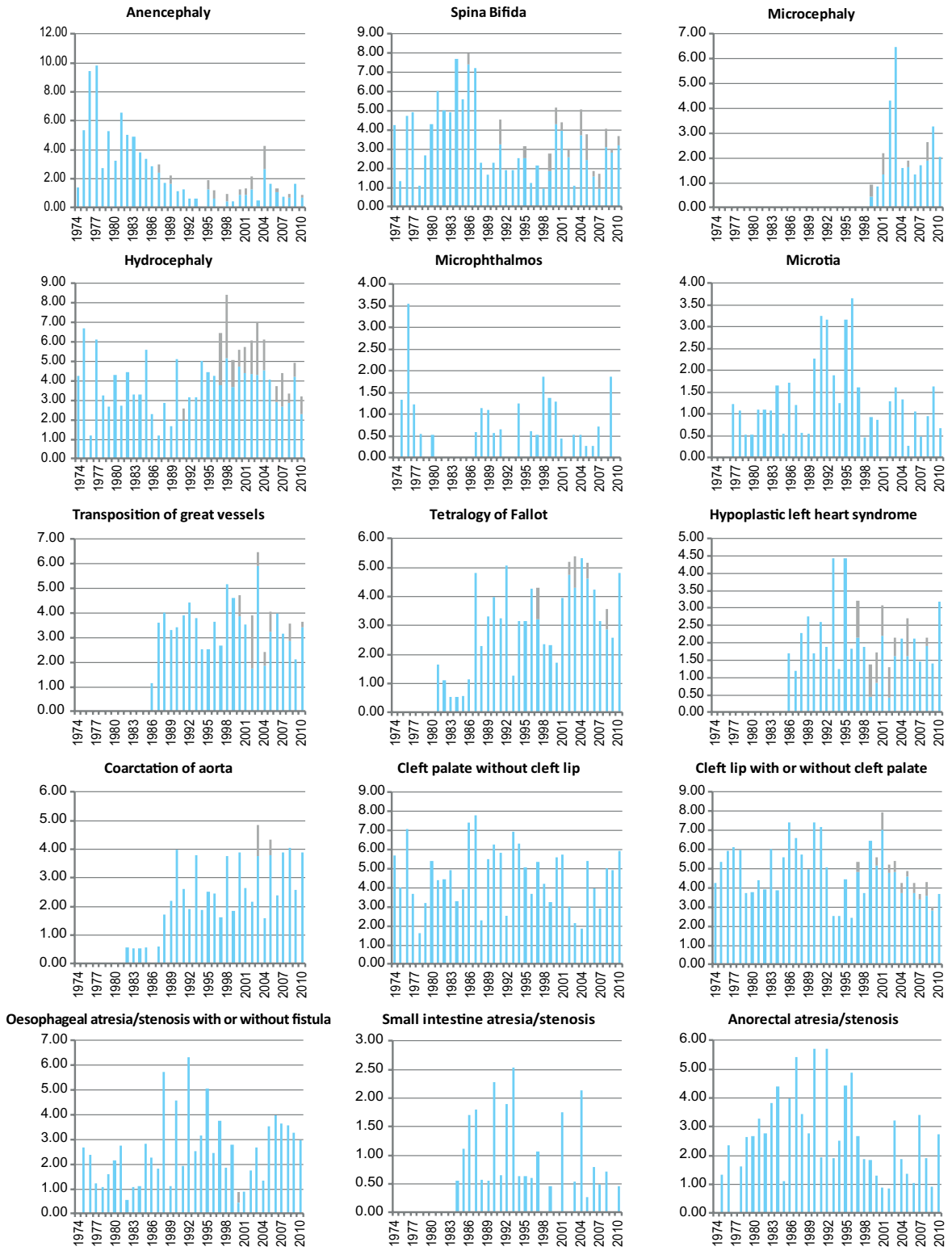
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**86,899**	**90,506**	**87,374**	**78,764**	**101,249**	**138,884**	**207,453**
Anencephaly	4.83	4.75	2.17	0.89	0.79	2.23	1.11
Spina bifida	3.11	5.86	4.23	2.79	2.57	3.74	2.89
Encephalocele	0.35	0.44	0.92	0.51	0.30	0.36	0.43
Microcephaly	nr	nr	0.00	0.00	0.40	2.88	2.22
Holoprosencephaly	nr	0.28*	0.11	0.51	0.00	0.29	0.34
Hydrocephaly	3.80	3.87	2.63	3.68	6.02	5.62	3.90
Anophthalmos	0.00	0.00	0.00	0.00	0.00	0.14	0.14
Microphthalmos	0.81	0.00	0.69	0.38	1.19	0.36	0.58
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.00	0.00	0.00	0.13	0.00	0.00	0.05
Microtia	0.58	1.10	1.26	2.54	1.38	0.86	0.96
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	nr	3.09	3.43	4.25	3.82	3.28
Tetralogy of Fallot	0.00*	0.88	3.09	3.17	2.86	5.04	3.66
Hypoplastic left heart syndrome	nr	nr	1.95	2.92	1.98	2.30	2.07
Coarctation of aorta	0.00*	0.44	1.72	2.54	2.77	3.02	3.37
Choanal atresia, bilateral	nr	0.28*	0.23	0.25	0.10	0.14	0.14
Cleft palate without cleft lip	4.03	4.20	5.84	5.33	4.44	3.67	4.58
Cleft lip with or without cleft palate	4.83	4.75	6.41	4.32	4.84	5.33	3.76
Oesophageal atresia/stenosis with or without fistula	1.61	1.66	3.09	3.81	2.27	2.09	3.47
Small intestine atresia/stenosis	nr	0.83*	1.37	1.27	0.40	1.01	0.48
Anorectal atresia/stenosis	1.84	3.09	4.23	3.30	2.37	1.58	2.02
Undescended testis (36 weeks of gestation or later)	nr	nr	0.00	0.00	0.00*	nr	7.73*
Hypospadias	28.42	26.52	34.68	41.77	36.44	34.27	36.44
Epispadias	0.12	0.11	0.00	0.25	0.20	0.22	0.10
Indeterminate sex	nr	nr	0.00	0.00	0.00*	0.27*	0.39*
Renal agenesis	nr	nr	0.69	0.89	0.49	0.94	0.82
Cystic kidney	0.46	0.99	1.26	1.14	1.78	2.02	2.22
Bladder exstrophy	0.12	0.22	0.92	0.25	0.30	0.50	0.24
Polydactyly, preaxial	0.23	0.66	0.46	0.38	1.19	1.01	0.77
Total Limb reduction defects (include unspecified)	3.11	3.09	2.63	3.55	1.09	2.45	1.83
Transverse	nr	0.69*	1.26	1.52	0.40	1.08	0.96
Preaxial	nr	0.69*	0.57	0.25	0.49	1.08	0.19
Postaxial	nr	0.41*	0.11	0.76	0.00	0.07	0.29
Intercalary	nr	0.28*	0.34	0.25	0.20	0.14	0.19
Mixed	nr	0.69*	0.34	0.76	0.00	0.07	0.10
Unspecified	nr	0.00*	0.00	0.00	0.00	0.00	0.10
Diaphragmatic hernia	2.15*	2.65	1.83	2.67	1.58	2.02	1.88
Omphalocele	1.61	2.54	0.80	1.27	0.40	0.94	0.67
Gastroschisis	0.00*	0.77	0.23	0.00	0.20	0.36	0.19
Unspecified Omphalocele/Gastroschisis	0.00*	0.00	0.00	0.00	0.10	0.07	0.00
Prune belly sequence	0.46	0.11	0.11	0.00	0.10	0.29	0.05
Trisomy 13	nr	0.83*	0.34	0.38	0.49	0.50	0.29
Trisomy 18	nr	0.55*	0.69	0.63	1.28	1.30	0.53
Down syndrome, all ages (include age unknown)	10.24	11.05	11.90	6.86	9.09	10.08	7.57
<20	nr	nr	nr	0.00	0.00	16.31	0.00*
20-24	nr	nr	nr	0.00	2.76	4.61	4.27*
25-29	nr	nr	nr	2.90	5.49	4.93	3.21*
30-34	nr	nr	nr	6.91	8.23	6.91	3.49*
35-39	nr	nr	nr	17.90	16.54	19.74	13.02*
40-44	nr	nr	nr	38.74	58.34	79.98	63.93*
45+	nr	nr	nr	79.37	81.97	92.17	80.00*
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

Israel: IBDSP

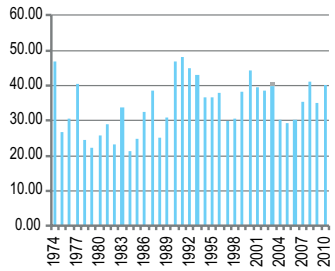
Time trends 1974-2009 (Birth prevalence rates per 10,000)



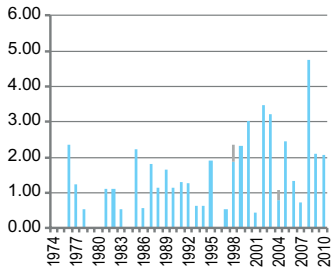
Note: L+S rates, ToP rates

Israel: IBDSP

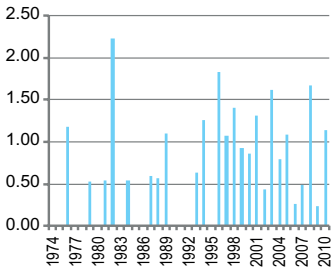
Hypospadias



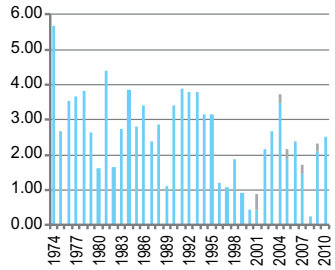
Cystic kidney



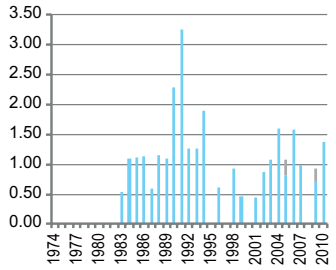
Polydactyly, preaxial



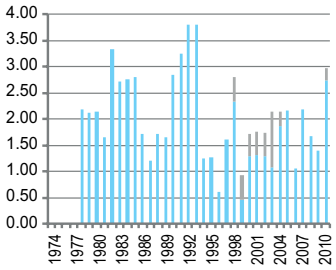
Limb reduction defects



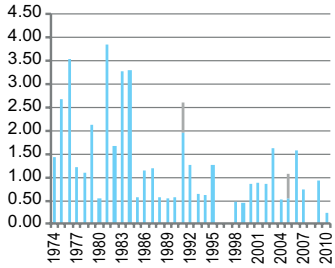
Limb reduction defects - transverse



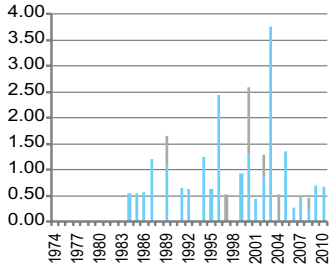
Diaphragmatic hernia



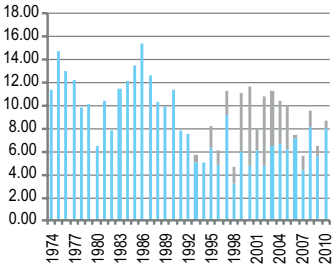
Omphalocele



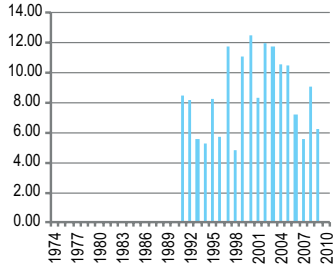
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Italy - Campania: BDRCam
Birth Defects Registry of Campania

History:
The Registry started in 1991 and became a full member of the ICBDSR in 1996.

Size and coverage:
The Registry is based on reporting from hospitals distributed in Campania, a region in southern Italy. Naples is the main city. Initially 38 hospitals reported and the annual number of births was 38.000. Until 2001 the registry is hospital-based covering approximately 50.000 annual births. Actually beginning from 2002, the registry is population based covering approximately 100% of all births. Stillbirths and induced abortions are included. In 2002 is started officially a link with birth regional registry (CEDAP).
After 2004 started a new link with Hospital discharge schedules registry (SDO). The last link allows to enclose the data after pediatric hospital discharge in the first year of life and to complete the birth data on baby with birth defects. Thus the birh defects ratio is about 5% and not 2%. Unfortunately, the data obtained from SDO registry allows to analyse only minimum data set (birh date, number of birth defects, mother's place of residence. No informations on exposure is possible.

Legislation and funding:
The Registry is a surveillance Programme supported by grants from Regional Health Authorities. Participation was voluntary up to 1995. From 1996 participation is mandatory.

Sources of ascertainment:
Reports are obtained from delivery units and pediatric clinics at the participating hospitals. For selected malformations multiple sources are used with follow-up to one year using specific records from pediatric specialities departments dealing with malformed infants.

Exposure information:
For each malformed infant reported, information is given on certain exposures, including maternal drug usage and parental occupation. Beginning from 2002 informations on controls are available but only partially on induced abortions.

Background information:
Always from 2002 background information is given on certain exposures, including maternal drug usage and parental occupation. Informations on controls are available.

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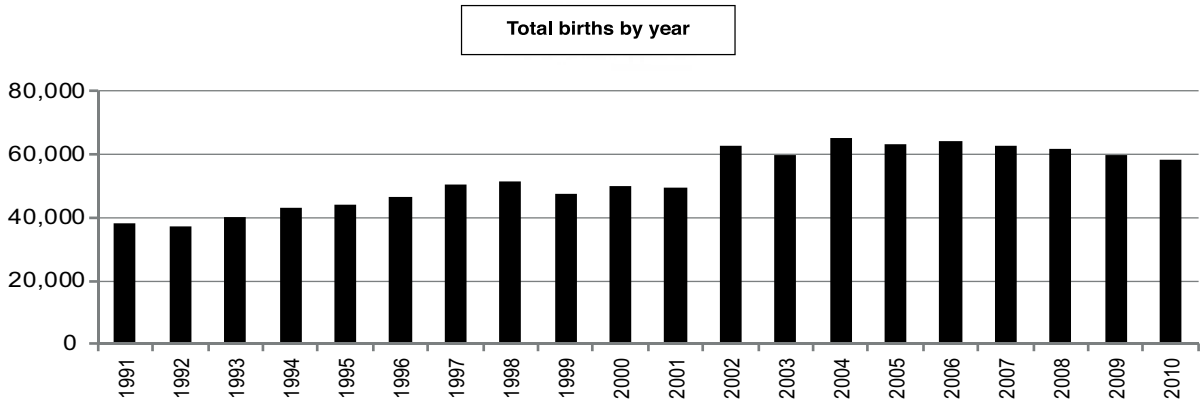
Italy: BDRCam



Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	63	94.0	Cystic kidney	5	5.1
Spina bifida	40	70.2	Limb reduction defects	20	29.0
Encephalocele	8	42.1	Diaphragmatic hernia	10	20.0
Holoprosencephaly	24	43.6	Omphalocele	20	76.9
Hydrocephaly	72	51.1	Gastroschisis	3	50.0
Hypoplastic left heart syndrome	41	68.3	Trisomy 13	12	85.7
Cleft palate without cleft lip	3	2.6	Trisomy 18	38	80.9
Cleft lip with or without cleft palate	15	12.3	Down syndrome	252	58.3
Renal agenesis	15	11.0			

Total ToPs with births defects = 960 (Ratio ToPs/Births: 5.34 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: BDRCam, 2010

Live births (LB)	58,212
Stillbirths (SB)	111
Total births	58,323
Number of terminations of pregnancy (ToP) for birth defects	316

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	19	3.26
Spina bifida	2	0	18	3.43
Encephalocele	8	0	3	1.89
Microcephaly	8	0	0	1.37
Holoprosencephaly	14	0	11	4.29
Hydrocephaly	13	0	31	7.54
Anophthalmos	1	0	0	0.17
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	6	0	0	1.03
Microtia	1	0	0	0.17
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	19	0	1	3.43
Tetralogy of Fallot	23	0	1	4.12
Hypoplastic left heart syndrome	8	0	14	3.77
Coarctation of aorta	25	0	0	4.29
Choanal atresia, bilateral	5	0	0	0.86
Cleft palate without cleft lip	35	0	1	6.17
Cleft lip with or without cleft palate	40	0	6	7.89
Oesophageal atresia/stenosis with or without fistula	14	0	2	2.74
Small intestine atresia/stenosis	17	0	1	3.09
Anorectal atresia/stenosis	14	0	0	2.40
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	8	0	0	1.37
Epispadias	0	0	0	0.00
Indeterminate sex	2	0	1	0.51
Renal agenesis	36	0	5	7.03
Cystic kidney	35	0	2	6.34
Bladder exstrophy	2	0	2	0.69
Polydactyly, preaxial	9	0	3	2.06
Total Limb reduction defects (include unspecified)	8	0	7	2.57
Transverse	5	0	2	1.20
Preaxial	0	0	1	0.17
Postaxial	0	0	0	0.00
Intercalary	0	0	1	0.17
Mixed	0	0	0	0.00
Unspecified	3	0	3	1.03
Diaphragmatic hernia	23	0	4	4.63
Omphalocele	2	0	10	2.06
Gastroschisis	1	0	0	0.17
Unspecified Omphalocele/Gastroschisis	1	0	0	0.17
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	7	1.20
Trisomy 18	2	0	20	3.77
Down syndrome, all ages (include age unknown)	55	0	85	24.00
<20	0	0	0	0.00
20-24	2	0	4	5.94
25-29	2	0	6	6.29
30-34	3	0	10	6.69
35-39	6	0	31	32.04
40-44	4	0	30	128.11
45+	0	0	4	465.12
unknown	38	0	0	---

nr = not reported

Italy-Campania: BDRCam, previous years rates 1991-2010

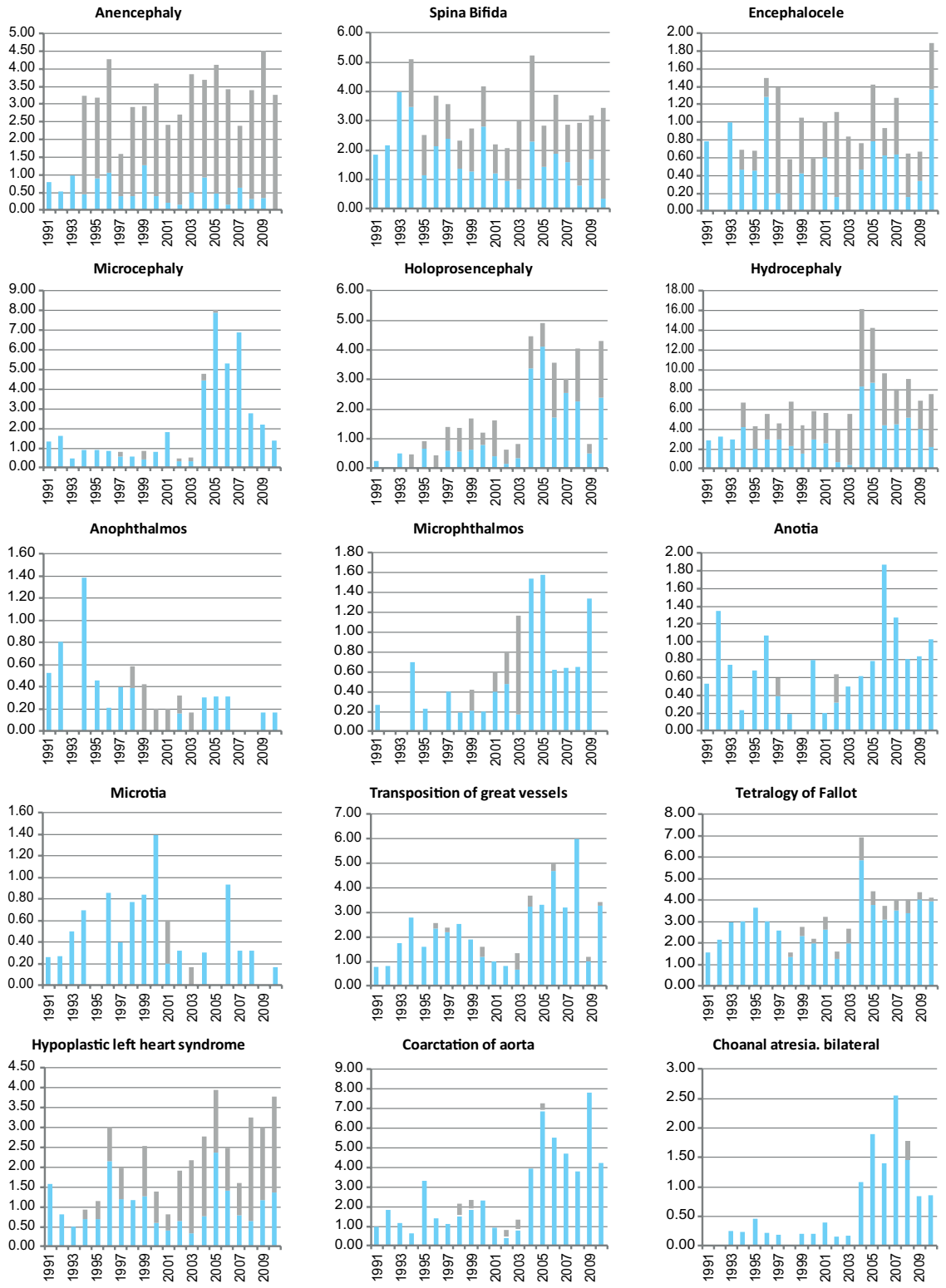
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births				**202,482**	**246,252**	**300,687**	**306,636**
Anencephaly				1.83	3.05	3.39	3.39
Spina bifida				3.16	3.33	3.13	3.26
Encephalocele				0.64	1.02	1.03	1.08
Microcephaly				1.04	0.77	3.23	3.75
Holoprosencephaly				0.44	1.22	2.56	3.16
Hydrocephaly				4.10	5.44	9.35	8.25
Anophthalmos				0.64	0.37	0.27	0.13
Microphthalmos				0.25	0.24	1.16	0.65
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.13	0.29
Anotia				0.69	0.53	0.57	1.17
Microtia				0.35	0.85	0.27	0.36
Unspecified Anotia/Microtia				0.00	0.00	0.17	0.07
Transposition of great vessels				1.58	2.19	2.10	3.78
Tetralogy of Fallot				2.72	2.40	3.82	4.04
Hypoplastic left heart syndrome				0.99	1.99	2.39	2.80
Coarctation of aorta				1.68	1.91	2.99	5.28
Choanal atresia, bilateral				0.20	0.16	0.76	1.50
Cleft palate without cleft lip				4.30	4.91	5.39	5.80
Cleft lip with or without cleft palate				7.06	7.23	6.62	6.62
Oesophageal atresia/stenosis with or without fistula				2.27	2.03	2.53	3.65
Small intestine atresia/stenosis				2.02	2.11	2.36	3.29
Anorectal atresia/stenosis				3.06	3.01	3.29	3.65
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				3.51	3.53	5.32	1.89
Epispadias				0.25	0.20	0.33	0.26
Indeterminate sex				0.40	0.69	0.80	0.85
Renal agenesis				1.93	3.37	5.92	7.47
Cystic kidney				1.78	2.60	4.42	6.00
Bladder exstrophy				0.35	0.16	0.20	0.29
Polydactyly, preaxial				1.78	1.87	4.29	4.76
Total Limb reduction defects (include unspecified)				5.28	5.08	4.66	3.78
Transverse				3.61	2.68	2.53	2.19
Preaxial				0.69	0.97	0.70	0.68
Postaxial				0.25	0.49	0.60	0.29
Intercalary				0.35	0.53	0.27	0.13
Mixed				0.15	0.12	0.07	0.16
Unspecified				0.00	0.08	0.00	0.42
Diaphragmatic hernia				1.98	2.44	2.93	3.07
Omphalocele				1.38	1.99	2.00	1.60
Gastroschisis				0.35	0.61	0.50	0.29
Unspecified Omphalocele/Gastroschisis				0.00	0.00	0.03	0.23
Prune belly sequence				0.00	0.13	0.10	0.23
Trisomy 13				0.84	0.61	0.93	0.65
Trisomy 18				1.04	1.95	2.26	2.28
Down syndrome, all ages (include age unknown)				12.54	13.08	15.23	22.31
<20				3.59	3.74	5.84*	0.00*
20-24				6.51	3.51	2.16*	4.93*
25-29				7.51	5.25	5.82*	5.14*
30-34				12.77	9.71	6.68*	10.15*
35-39				36.46	28.39	30.16*	33.44*
40-44				102.45	125.31	83.63*	139.38*
45+				197.37	226.24	203.39*	366.97*
unknown				---	---	---	---

nr = not reported
* data include less than 5 years

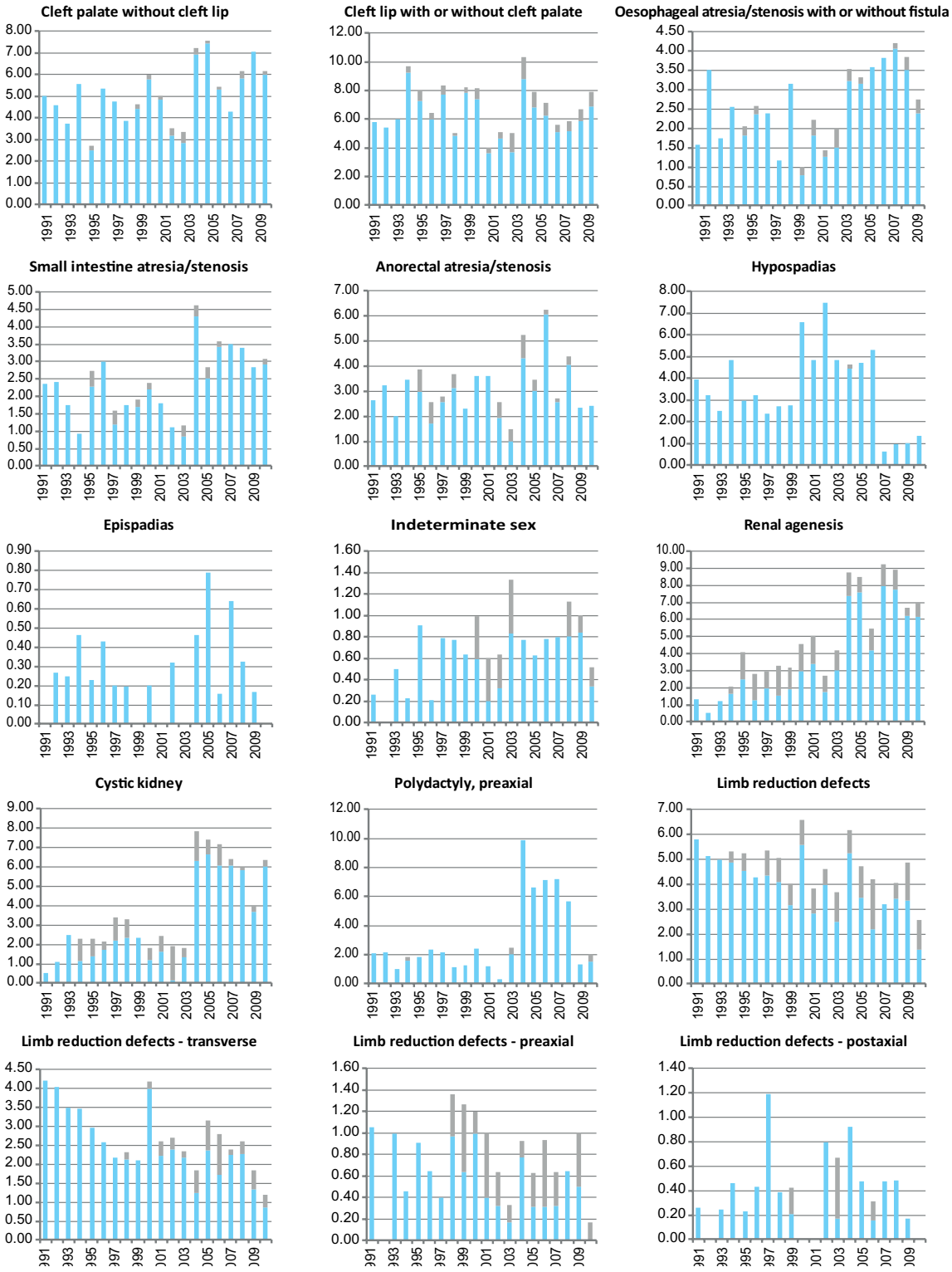
Italy-Campania: BDRCam

Time trends 1991-2010 (Birth prevalence rates per 10,000)



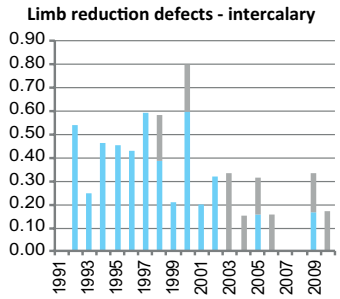
Note: L+S rates, ToP rates

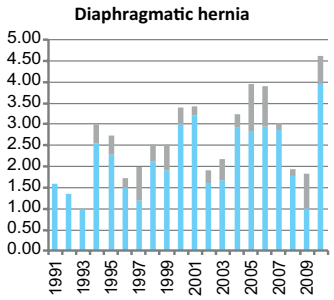
Italy-Campania: BDRCam

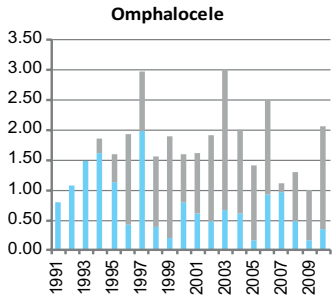


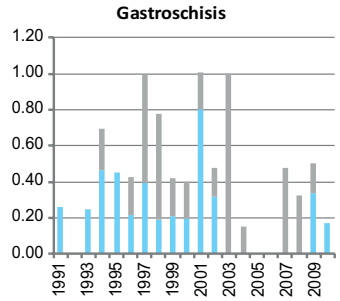
Note: L+S rates, ToP rates

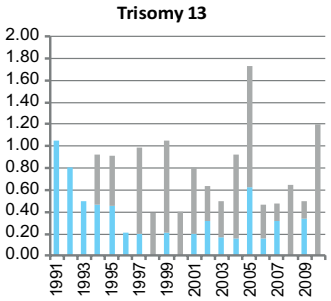
Italy-Campania: BDRCam

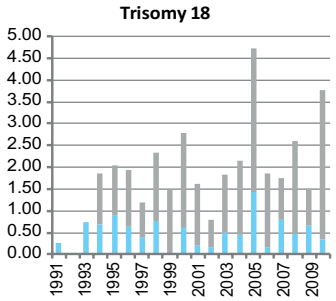


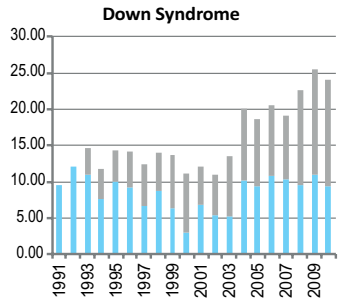












Note: L+S rates, ToP rates

Italy-Emilia Romagna: IMER

Emilia Romagna Registry of Congenital Malformations

History:
The registry was started in 1978 in a few hospitals and has increased in size to now include 45 delivery units. The Programme became an associate member of the Clearinghouse in 1985.

Size and coverage:
The Programme is based on approximately 90% of all births in the Emilia-Romagna region, or approximately 25,000 annual births (4% of all births in Italy). Stillbirths of 28 weeks or more gestation are included.

Legislation and funding:
The Programme is recognised and financed by the health authorities, the National Research Council, and the Regional Health Council. Hospital participation is voluntary.

Sources of ascertainment:
Reporting is made by neonatologists and pediatricians during the first week of the infant's life. Selected malformations are followed up.

Exposure information:
Detailed exposure information is obtained by interviews of the mothers of malformed infants. For each malformed infant, a control is chosen (the baby born before or after the malformed case in the same hospital) and its mother is interviewed in a similar way.

Background information:
Some general demographic information is known for all births in the area. For each participating hospital, the number of livebirths and stillbirths are known.

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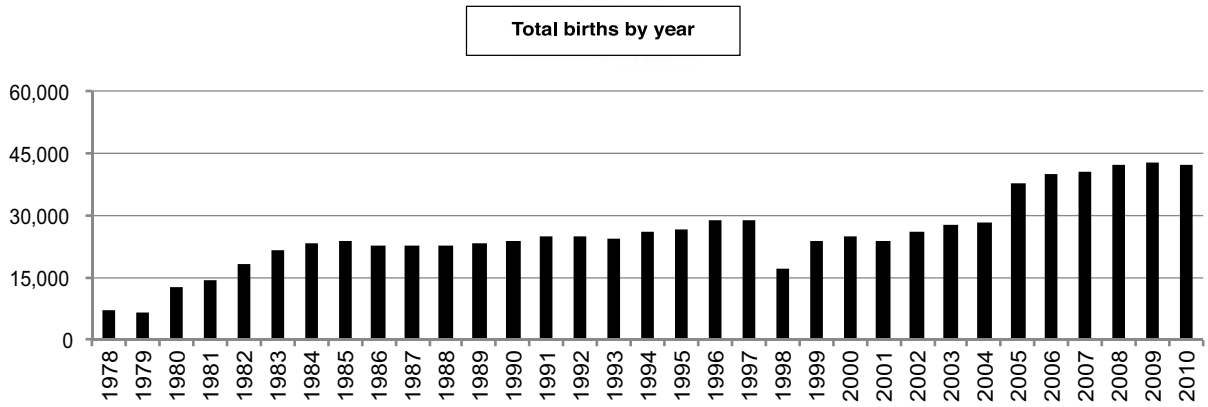
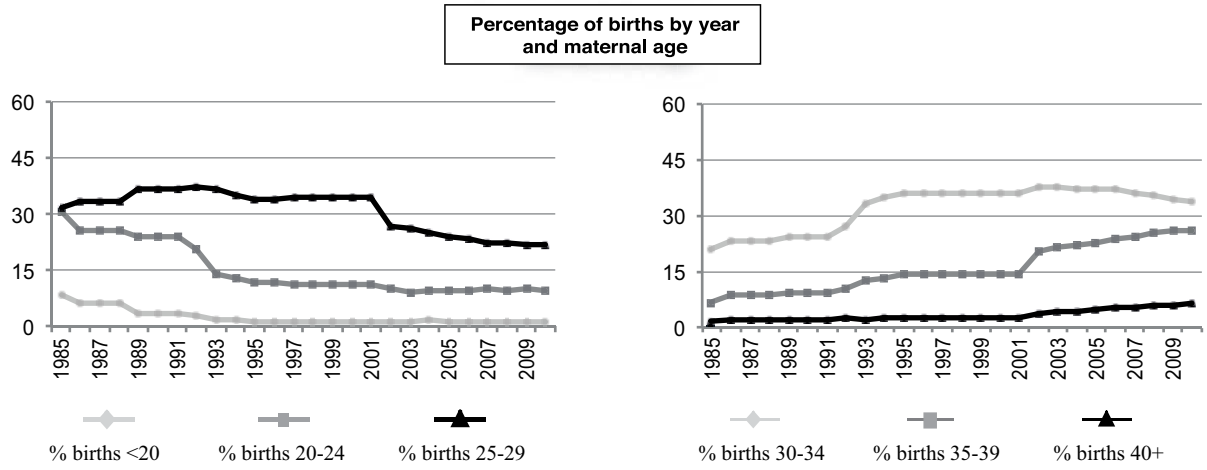
Fax: 39-051-342754
E-mail: guido.cocchi@unibo.it

Website: http://www.unife.it/imer/

Italy-Emilia Romagna: IMER





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	23	85.2	Cystic kidney	4	9.5
Spina bifida	18	54.5	Limb reduction defects	15	30.0
Encephalocele	6	60.0	Diaphragmatic hernia	7	17.5
Holoprosencephaly	12	80.0	Omphalocele	14	46.7
Hydrocephaly	24	42.9	Gastroschisis	1	7.7
Hypoplastic left heart syndrome	11	55.0	Trisomy 13	11	91.7
Cleft palate without cleft lip	1	1.6	Trisomy 18	36	76.6
Cleft lip with or without cleft palate	14	13.5	Down syndrome	181	68.0
Renal agenesis	5	20.0			

Total ToPs with births defects = 404 (Ratio ToPs/Births: 3.17 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy-Emilia Romagna: IMER, 2010

Live births (LB)	42,043
Stillbirths (SB)	111
Total births	42,154
Number of terminations of pregnancy (ToP) for birth defects	194

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	5	1.42
Spina bifida	5	0	2	1.66
Encephalocele	0	0	3	0.71
Microcephaly	9	0	0	2.14
Holoprosencephaly	1	0	9	2.37
Hydrocephaly	16	1	8	5.93
Anophthalmos	2	0	1	0.71
Microphthalmos	3	0	1	0.95
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	1	0	0	0.24
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	19	0	2	4.98
Tetralogy of Fallot	14	0	1	3.56
Hypoplastic left heart syndrome	2	0	2	0.95
Coarctation of aorta	18	0	0	4.27
Choanal atresia, bilateral	4	0	0	0.95
Cleft palate without cleft lip	24	0	1	5.93
Cleft lip with or without cleft palate	33	1	4	9.01
Oesophageal atresia/stenosis with or without fistula	19	0	0	4.51
Small intestine atresia/stenosis	14	0	0	3.32
Anorectal atresia/stenosis	8	0	0	1.90
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	73	0	0	17.32
Epispadias	2	0	0	0.47
Indeterminate sex	4	0	0	0.95
Renal agenesis	3	0	1	0.95
Cystic kidney	10	0	1	2.61
Bladder exstrophy	1	0	0	0.24
Polydactyly, preaxial	2	0	0	0.47
Total Limb reduction defects (include unspecified)	14	0	6	4.74
Transverse	9	0	5	3.32
Preaxial	3	0	0	0.71
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.24
Mixed	0	0	0	0.00
Unspecified	1	0	1	0.47
Diaphragmatic hernia	7	0	3	2.37
Omphalocele	6	0	3	2.14
Gastroschisis	5	0	1	1.42
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	1	1	0.47
Trisomy 18	3	1	7	2.61
Down syndrome, all ages (include age unknown)	32	0	53	20.16
<20	0	0	0	0.00
20-24	1	0	1	4.86
25-29	6	0	1	7.60
30-34	6	0	7	9.13
35-39	9	0	19	25.75
40-44	10	0	22	121.63
45+	0	0	2	118.34
unknown	0	0	1	---

nr = not reported

Italy-Emilia Romagna: IMER, Previous years rates 1978 - 2010

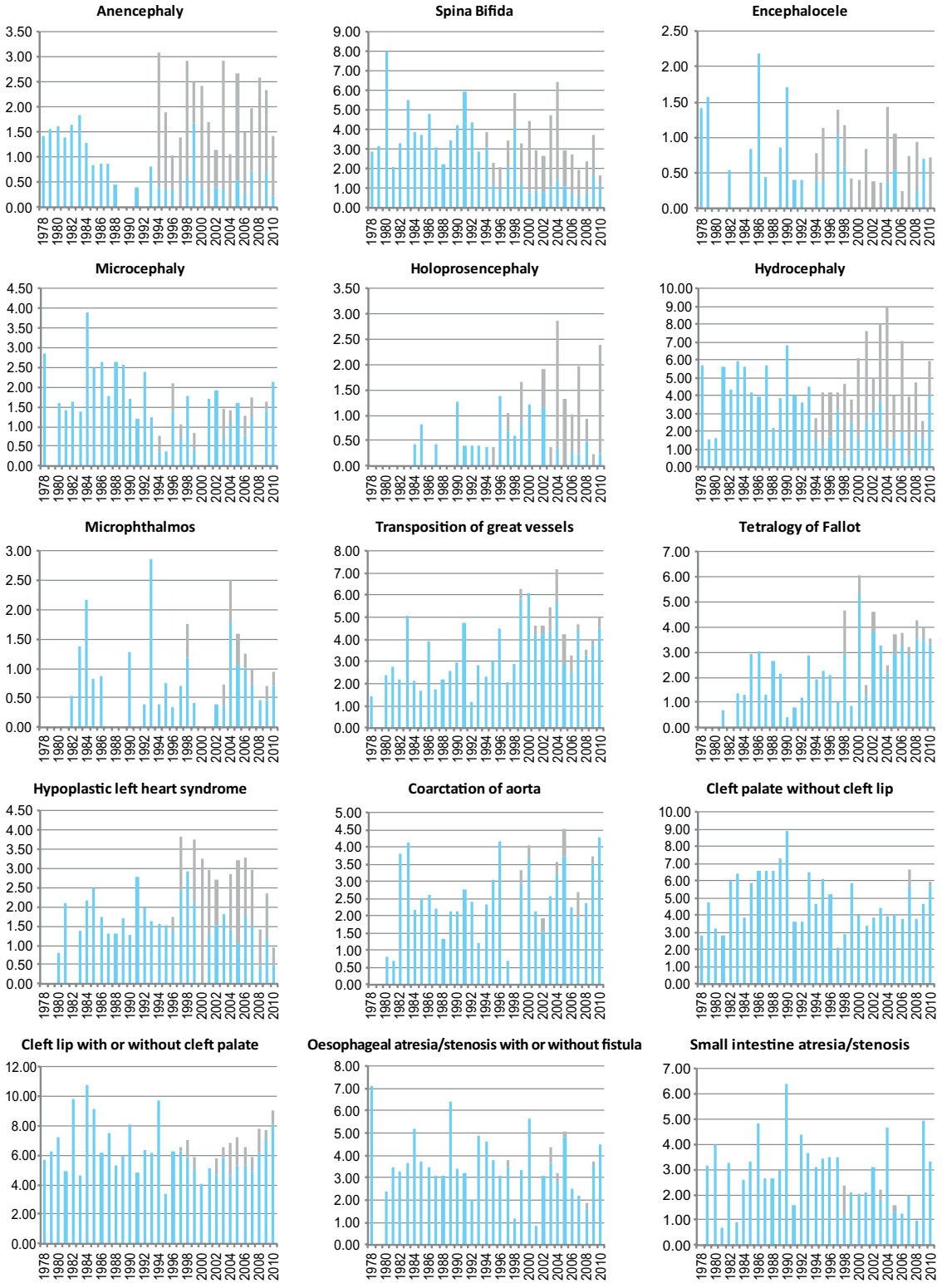
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**25,878**	**101,626**	**115,334**	**126,943**	**123,541**	**142,659**	**207,832**
Anencephaly	1.55	1.38	0.43	1.26	1.94	1.96	1.97
Spina bifida	5.41	3.84	3.55	3.86	3.64	3.93	2.50
Encephalocele	0.77	0.30	1.04	0.55	0.65	0.84	0.67
Microcephaly	1.55	2.26	2.25	1.18	1.13	1.61	1.35
Holoprosencephaly	0.00	0.30	0.35	0.39	1.21	1.33	1.30
Hydrocephaly	2.71	5.12	4.51	3.78	4.53	6.52	4.81
Anophthalmos	0.39	0.30	0.09	0.24	0.24	0.35	0.14
Microphthalmos	0.00	1.08	0.43	0.87	0.57	1.12	0.87
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.14
Anotia	nr	nr	nr	0.77*	0.65	1.12	0.38
Microtia	nr	nr	nr	1.15*	0.40	0.77	0.58
Unspecified Anotia/Microtia	nr	nr	nr	0.00*	0.00	0.00	0.00
Transposition of great vessels	1.55	2.76	2.69	2.84	4.37	5.19	4.09
Tetralogy of Fallot	0.00	1.38	1.91	1.81	2.75	3.22	3.75
Hypoplastic left heart syndrome	0.39	1.67	1.47	1.89	3.08	2.73	2.17
Coarctation of aorta	0.80	2.76	2.08	2.36	2.59	3.08	3.08
Choanal atresia, bilateral	0.00	0.20	0.35	0.24	0.24	0.49	0.38
Cleft palate without cleft lip	3.48	5.12	7.20	4.88	4.05	3.93	4.96
Cleft lip with or without cleft palate	6.57	8.07	6.59	6.07	5.91	6.38	7.41
Oesophageal atresia/stenosis with or without fistula	3.09	3.94	3.90	3.70	3.56	3.50	2.98
Small intestine atresia/stenosis	2.71	2.26	3.90	3.23	2.75	2.66	2.50
Anorectal atresia/stenosis	0.39	3.35	3.12	2.99	2.67	3.72	1.59
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	20.87	18.89	20.64	17.27*	16.59	16.12	15.25
Epispadias	nr	nr	nr	0.00*	0.00	0.00	0.19
Indeterminate sex	nr	nr	nr	0.00*	0.24	0.56	0.48
Renal agenesis	3.09	0.98	1.56	1.50	3.08	4.28	2.98
Cystic kidney	0.39	0.59	0.78	0.39	4.21	4.49	3.51
Bladder exstrophy	0.77	0.30	0.69	0.08	0.24	0.21	0.34
Polydactyly, preaxial	9.27	9.64	7.37	6.14	3.89	2.59	2.21
Total Limb reduction defects (include unspecified)	nr	6.25*	5.72	4.73	4.45	4.98	4.43
Transverse	nr	4.16*	3.12	2.44	2.02	1.61	2.40*
Preaxial	nr	0.00*	0.78	0.79	1.13	0.91	0.88*
Postaxial	nr	0.42*	0.61	0.47	0.49	0.77	0.00*
Intercalary	nr	0.42*	0.78	0.47	0.57	0.42	0.24*
Mixed	nr	0.42*	0.35	0.32	0.08	0.21	0.08*
Unspecified	nr	0.83*	0.09	0.24	0.16	1.05	0.64*
Diaphragmatic hernia	1.16	1.67	2.08	3.15	3.24	2.80	2.84
Omphalocele	2.32	1.57	1.82	2.05	1.70	2.52	2.17
Gastroschisis	0.00	0.98	0.78	0.95	0.73	1.19	1.01
Unspecified Omphalocele/Gastroschisis	0.39	0.49	1.13	0.16	0.00	0.00	0.00
Prune belly sequence	0.39	0.49	0.26	0.24	0.40	0.14	0.05
Trisomy 13	1.16	1.38	0.87	0.71	0.89	1.89	1.20
Trisomy 18	0.39	1.38	1.04	1.26	2.35	4.70	4.04
Down syndrome, all ages (include age unknown)	17.78	13.48	12.40	15.83	19.43	18.65	19.87
<20	nr	0.00*	3.36	6.68	13.25	14.49	6.56
20-24	nr	4.05*	5.19	5.73	9.88	5.64	4.42
25-29	nr	13.21*	9.43	9.85	5.90	4.45	5.87
30-34	nr	14.01*	16.42	13.67	13.02	11.37	9.60
35-39	nr	62.15*	27.93	34.53	46.97	36.18	34.69
40-44	nr	55.40*	61.64	125.33	161.68	107.70	93.43
45+	nr	333.33*	0.00	165.29	198.68	86.58	135.36
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

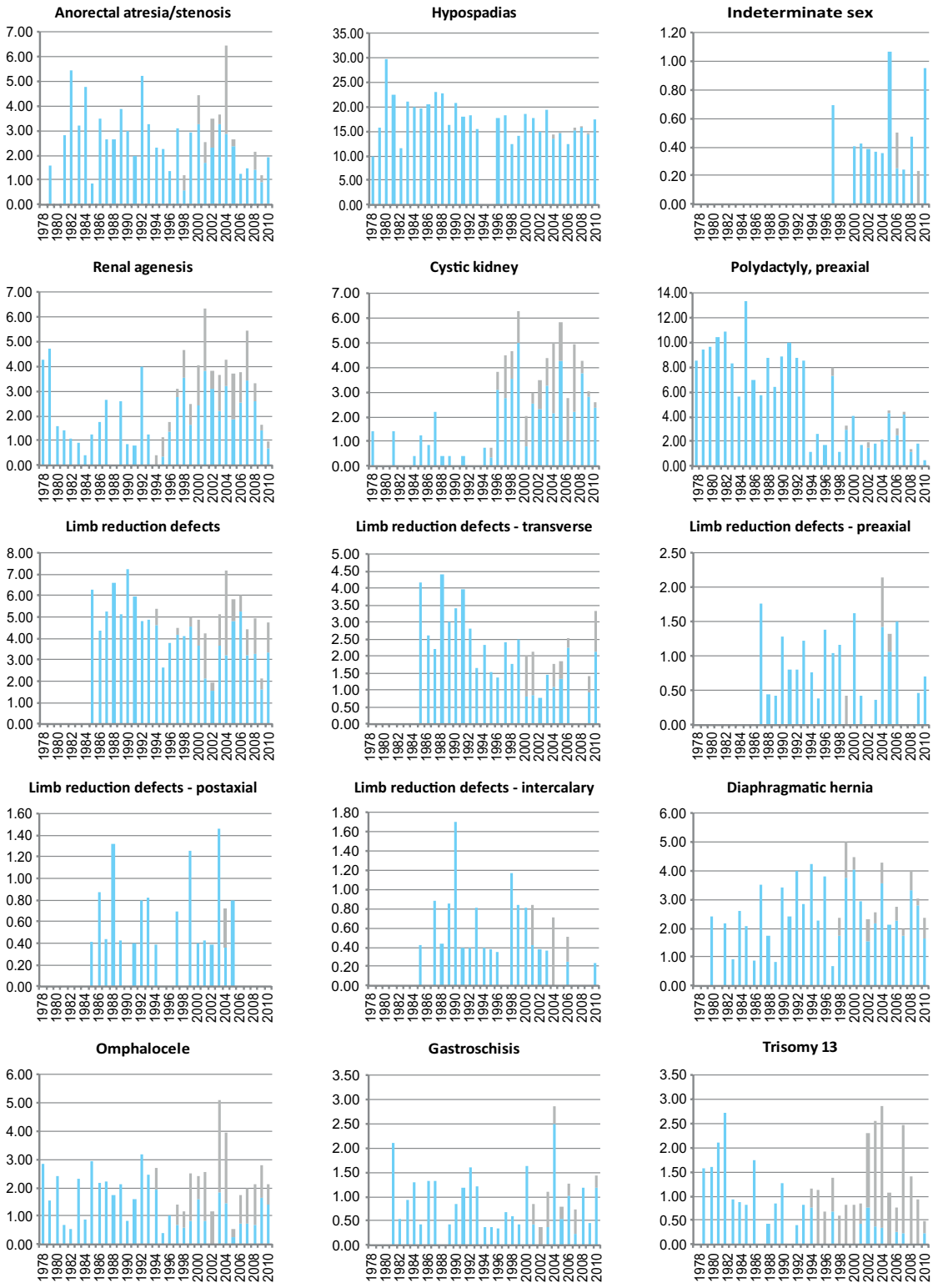
Italy-Emilia Romagna: IMER

Time trends 1978-2010 (Birth prevalence rates per 10,000)



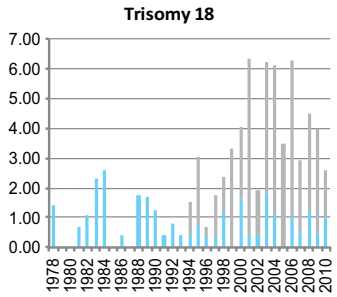
Note: L+S rates, ToP rates

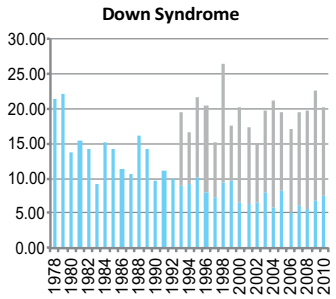
Italy-Emilia Romagna: IMER

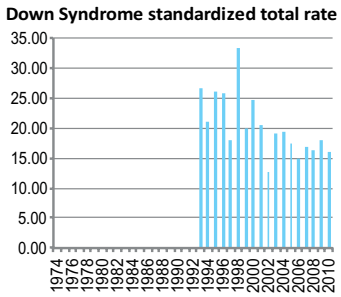


Note: L+S rates, ToP rates

Italy-Emilia Romagna: IMER







Note: L+S rates, ToP rates

ITALY-Lombardy: CMRL
Congenital Malformation Registry of Northern Lombardy

History:
The Registry started in 2000 and is located in National Cancer Institute of Milan. The Registry is full member of ICBDSR since 2007.

Size and Coverage:
The Registry is population-based and registers about 24 700 births annually, constituting 100% of the total annual births in the Provinces of Sondrio, Varese, Como and the northern part of Milan (HLA1). This is about 25% of the total annual births in the Region of Lombardy, and the 4.3% of total births in Italy.

Legislation and Funding:
The Registry is a research programme approved by the Italian Ministry of Health and supported by funding from the Italian National Cancer Institute.

Source of Ascertainment:
The registry uses active data collection methods from multiple sources (death certificates, hospital discharge records, pathology reports, birth certificates, outpatient drug prescription records, outpatient records, the social security list of the Region of Lombardy and clinical records).

The registry data are routinely cross-checked with the social security list of the Lombardy Region to up-date case (vital status) and parent information (age, vital status, etc.).

Exposure Information:
Information on exposure is not collected routinely can be collected on specific indications.

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ITALY-Lombardy: CMRL, 2010*

Live births (LB)	5,707
Stillbirths (SB)	10
Total births	5,717
Number of terminations of pregnancy (ToP) for birth defects	20

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	2	3.50
Spina bifida	2	0	0	3.50
Encephalocele	0	0	0	0.00
Microcephaly	3	0	1	7.00
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	2	0	2	7.00
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	1.75
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	2	0	0	3.50
Tetralogy of Fallot	1	0	0	1.75
Hypoplastic left heart syndrome	1	0	1	3.50
Coarctation of aorta	1	0	0	1.75
Choanal atresia, bilateral	1	0	0	1.75
Cleft palate without cleft lip	3	0	0	5.25
Cleft lip with or without cleft palate	2	0	0	3.50
Oesophageal atresia/stenosis with or without fistula	3	0	0	5.25
Small intestine atresia/stenosis	2	0	0	3.50
Anorectal atresia/stenosis	3	0	0	5.25
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	15	0	0	26.24
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	1.75
Renal agenesis	4	0	0	7.00
Cystic kidney	0	0	0	0.00
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	3	0	0	5.25
Total Limb reduction defects (include unspecified)	2	0	4	10.50
Transverse	0	0	1	1.75
Preaxial	0	0	1	1.75
Postaxial	0	0	1	1.75
Intercalary	0	0	1	1.75
Mixed	0	0	0	0.00
Unspecified	2	0	0	3.50
Diaphragmatic hernia	3	0	0	5.25
Omphalocele	1	0	0	1.75
Gastroschisis	1	0	0	1.75
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	0	0.00
Trisomy 18	0	0	3	5.25
Down syndrome, all ages (include age unknown)	5	0	8	22.74
<20	0	0	0	0.00
20-24	0	0	0	0.00
25-29	0	0	0	0.00
30-34	1	0	0	4.86
35-39	2	0	3	32.01
40-44	2	0	5	225.81
45+	0	0	0	0.00
unknown	0	0	0	---

nr = not reported
(*) Data for the Como province

Italy-Tuscany: RTDC
Tuscany Registry of Congenital Defects

History:
The registry started in 1979 in the province of Florence and from 1992 in the whole Tuscany region. The Programme became a full member of the Clearinghouse in 1998.

Size and coverage:
The Programme is population based, involves all the regional hospitals and the coverage is around 95% of all births in the Tuscany region (approximately 3.5 millions inhabitants and 25,000 births/year). Stillbirths of 20 weeks or more gestation and induced abortions after prenatal diagnosis of birth defects are systematically included. Malformed babies diagnosed within the first year of life are also registered.

Legislation and funding:
The Registry is a surveillance Programme included in the Regional Statistics System; it is formally recognised and supported by the Tuscany Region Health Authority.

Sources and ascertainment:
Multiple sources are used to ascertain malformed infants; records are obtained from all obstetrical and maternity units, pediatric departments, neonatal and pediatric surgery units, prenatal diagnostic centers and pathology services. Mothers are interviewed by using a standardized questionnaire.

Exposure information:
Exposure information on maternal and paternal occupation, life-style, and socio-economical characteristics are obtained by interviews of mothers of malformed infants.

Background information:
Vital statistics and other epidemiological information are obtained by the birth medical records collected by the Regional Bureau of Statistics. Selected information is obtained from the control material collected.

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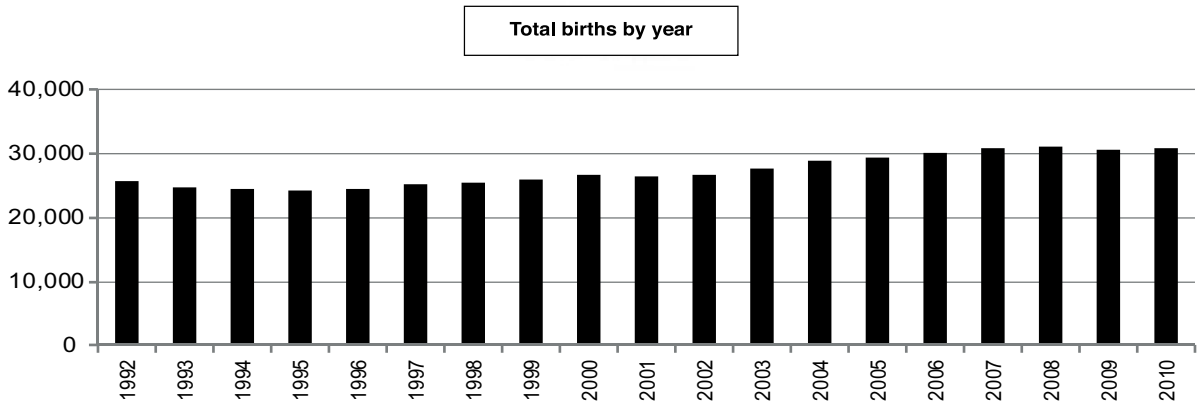
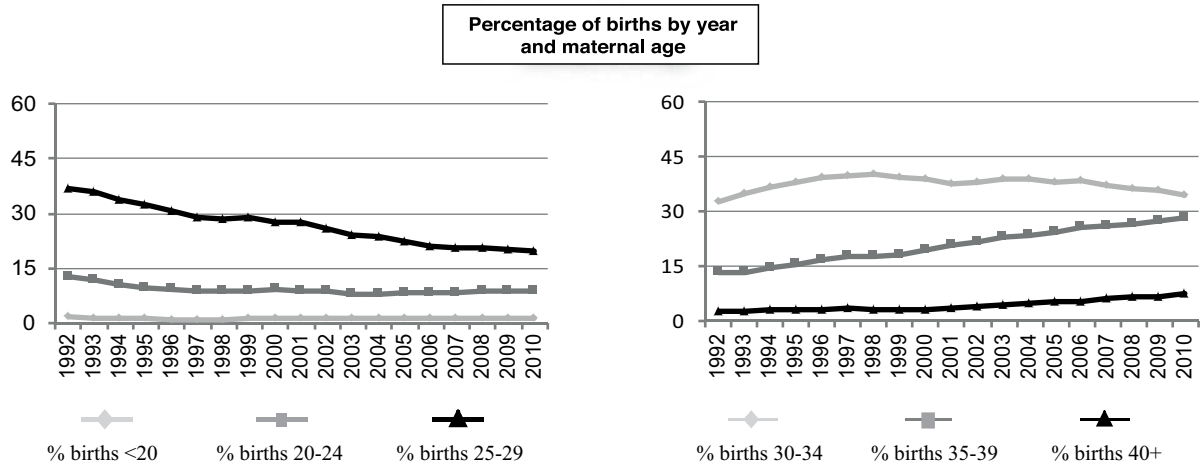
Italy-Tuscany: RTDC





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	14	100.0	Cystic kidney	8	20.0
Spina bifida	23	79.3	Limb reduction defects	11	28.2
Encephalocele	2	22.2	Diaphragmatic hernia	5	21.7
Holoprosencephaly	8	80.0	Omphalocele	16	84.2
Hydrocephaly	13	44.8	Gastroschisis	3	50.0
Hypoplastic left heart syndrome	17	63.0	Trisomy 13	17	94.4
Cleft palate without cleft lip	2	7.1	Trisomy 18	44	91.7
Cleft lip with or without cleft palate	11	19.3	Down syndrome	150	70.8
Renal agenesis	7	87.5			

Total ToPs with births defects = 441 (Ratio ToPs/Births: 4.77 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy-Tuscany: RTDC, 2010

Live births (LB)	30,769
Stillbirths (SB)	67
Total births	30,836
Number of terminations of pregnancy (ToP) for birth defects	159

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	3	0.97
Spina bifida	3	0	9	3.89
Encephalocele	4	0	0	1.30
Microcephaly	2	0	1	0.97
Holoprosencephaly	0	0	6	1.95
Hydrocephaly	9	0	3	3.89
Anophthalmos	0	0	0	0.00
Microphthalmos	3	0	0	0.97
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.65
Microtia	1	0	0	0.32
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	12	0	2	4.54
Tetralogy of Fallot	9	0	1	3.24
Hypoplastic left heart syndrome	5	1	6	3.89
Coarctation of aorta	10	0	0	3.24
Choanal atresia, bilateral	1	0	0	0.32
Cleft palate without cleft lip	5	0	0	1.62
Cleft lip with or without cleft palate	12	0	1	4.22
Oesophageal atresia/stenosis with or without fistula	8	0	0	2.59
Small intestine atresia/stenosis	6	0	0	1.95
Anorectal atresia/stenosis	7	0	0	2.27
Undescended testis (36 weeks of gestation or later)	17	0	0	5.51
Hypospadias	46	0	0	14.92
Epispadias	0	0	0	0.00
Indeterminate sex	3	0	1	1.30
Renal agenesis	1	0	2	0.97
Cystic kidney	11	0	2	4.22
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	0	1	1	0.65
Total Limb reduction defects (include unspecified)	8	0	2	3.24
Transverse	6	0	1	2.27
Preaxial	2	0	1	0.97
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	0	0	0	0.00
Diaphragmatic hernia	7	0	4	3.57
Omphalocele	2	0	2	1.30
Gastroschisis	1	0	2	0.97
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.32
Trisomy 13	1	0	5	1.95
Trisomy 18	0	1	19	6.49
Down syndrome, all ages (include age unknown)	22	1	55	25.30
<20	1	0	0	28.65
20-24	2	0	1	11.12
25-29	4	1	3	13.06
30-34	3	0	8	10.33
35-39	5	0	30	40.37
40-44	4	0	12	72.96
45+	2	0	1	227.27
unknown	1	0	0	---

Italy-Tuscany: RTDC, Previous years rates 1992 - 2010

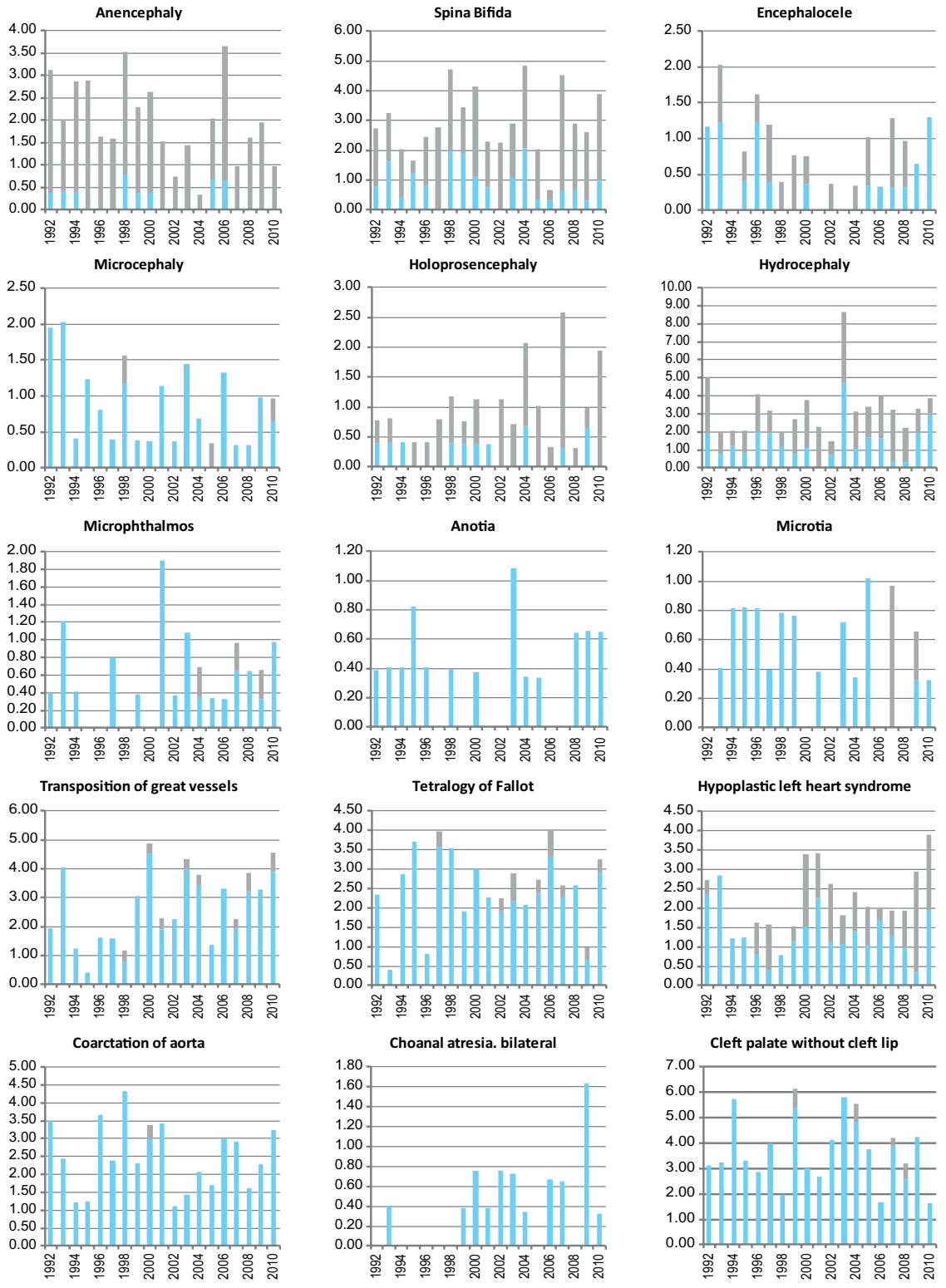
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995*	1996-2000	2001-2005	2006-2010
Total births				**99,132**	**127,970**	**139,053**	**153,584**
Anencephaly				2.72	2.34	1.22	1.82
Spina bifida				2.42	3.52	2.88	2.93
Encephalocele				1.01	0.94	0.36	0.91
Microcephaly				1.41	0.70	0.79	0.78
Holoprosencephaly				0.61	0.86	1.08	1.24
Hydrocephaly				2.82	3.13	3.81	3.32
Anophthalmos				0.00	0.23	0.07	0.13
Microphthalmos				0.50	0.23	0.86	0.72
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.07	0.00
Anotia				0.50	0.23	0.36	0.39
Microtia				0.50	0.55	0.50	0.39
Unspecified Anotia/Microtia				0.00	0.00	0.00	0.00
Transposition of great vessels				1.92	2.50	2.80	3.45
Tetralogy of Fallot				2.32	2.66	2.45	2.67
Hypoplastic left heart syndrome				2.02	1.80	2.45	2.54
Coarctation of aorta				2.12	3.20	1.94	2.60
Choanal atresia, bilateral				0.10	0.23	0.43	0.65
Cleft palate without cleft lip				3.83	3.59	4.39	3.00
Cleft lip with or without cleft palate				7.46	6.72	5.90	5.34
Oesophageal atresia/stenosis with or without fistula				2.32	2.66	2.23	2.28
Small intestine atresia/stenosis				1.01	0.55	1.22	1.30
Anorectal atresia/stenosis				1.61	2.34	2.73	1.95
Undescended testis (36 weeks of gestation or later)				4.44	7.19	8.41	6.12
Hypospadias				5.55	3.05	7.34	12.05
Epispadias				0.30	0.16	0.29	0.20
Indeterminate sex				1.01	0.55	0.36	0.85
Renal agenesis				1.61	1.41	0.86	0.78
Cystic kidney				3.13	3.59	4.10	4.49
Bladder exstrophy				0.30	0.23	0.14	0.26
Polydactyly, preaxial				0.91	1.25	0.86	1.11
Total Limb reduction defects (include unspecified)				5.04	5.47	5.68	4.30
Transverse				3.63	3.28	3.60	2.73
Preaxial				0.20	0.39	0.58	0.65
Postaxial				0.10	0.47	0.14	0.33
Intercalary				0.20	0.70	0.43	0.20
Mixed				0.50	0.47	0.07	0.07
Unspecified				0.00	0.00	1.08	0.91
Diaphragmatic hernia				1.41	1.41	2.16	2.21
Omphalocele				2.12	1.48	1.58	2.08
Gastroschisis				0.40	0.55	0.50	0.98
Unspecified Omphalocele/Gastroschisis				0.30	0.47	0.07	0.13
Prune belly sequence				0.10	0.16	0.00	0.20
Trisomy 13				0.50	0.94	1.08	1.95
Trisomy 18				2.32	3.75	2.66	4.36
Down syndrome, all ages (include age unknown)				14.22	16.25	16.40	19.99
<20				0.00	0.00	0.00	10.66
20-24				8.35	2.64	4.31	8.28
25-29				8.31	8.21	2.93	6.37
30-34				12.21	11.84	8.30	7.67
35-39				28.51	29.00	27.12	29.74
40-44				64.03	119.47	136.40	92.24
45+				238.10	0.00	201.01	177.38
unknown				---	---	---	---

* data include less than 5 years

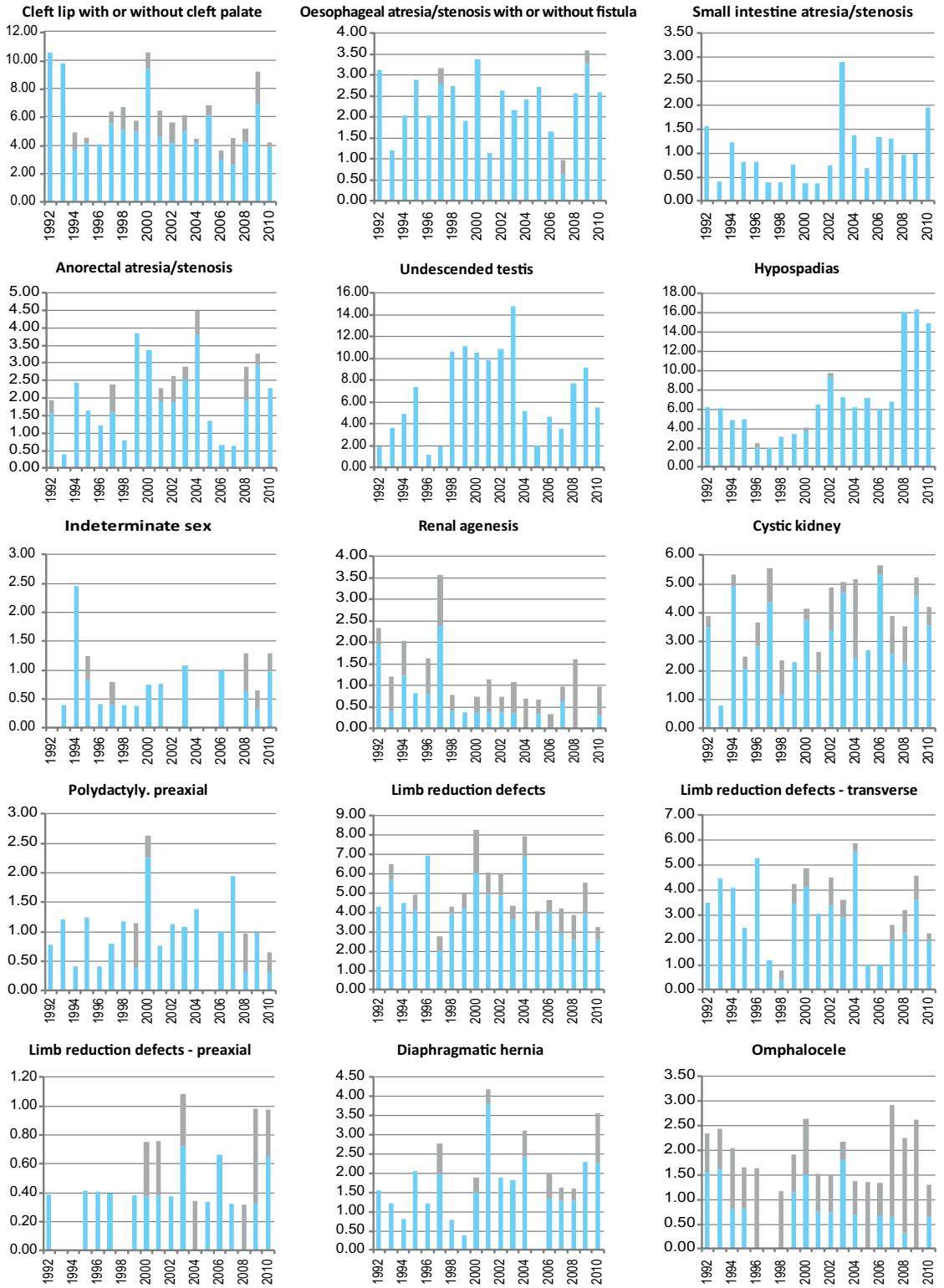
Italy-Tuscany: RTDC

Time trends 1992-2010 (Birth prevalence rates per 10,000)



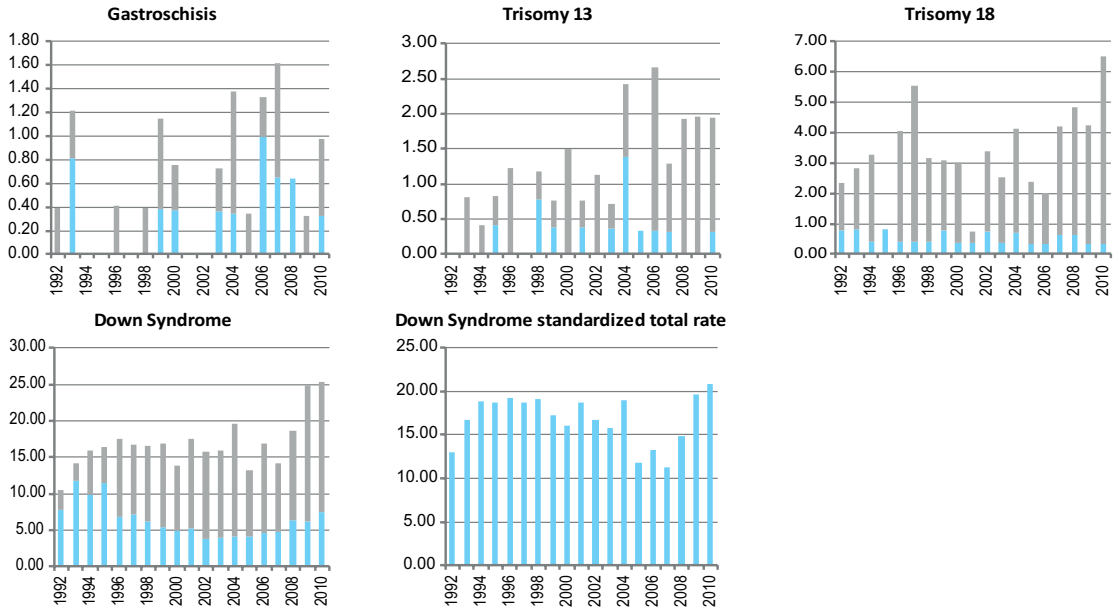
Note: L+S rates, ToP rates

Italy-Tuscany: RTDC



Note: L+S rates, ToP rates

Italy-Tuscany: RTDC



Note: L+S rates, ToP rates

Japan: JAOG

Japan Association of Obstetricians and Gynaecologists

History:
The Programme started in 1972 and became a full member of the Clearinghouse in 1988.

Size and coverage:
The Programme is based on reports from 270 hospitals throughout Japan. At present approximately 100,000 births are covered, representing about 9% of all Japanese births. Stillbirths of 22 weeks or more gestation are included.

Legislation and funding:
The Programme is a research Programme acknowledged by the Ministry of Welfare and supported by the Japanese Association of Obstetricians and Gynecologists.

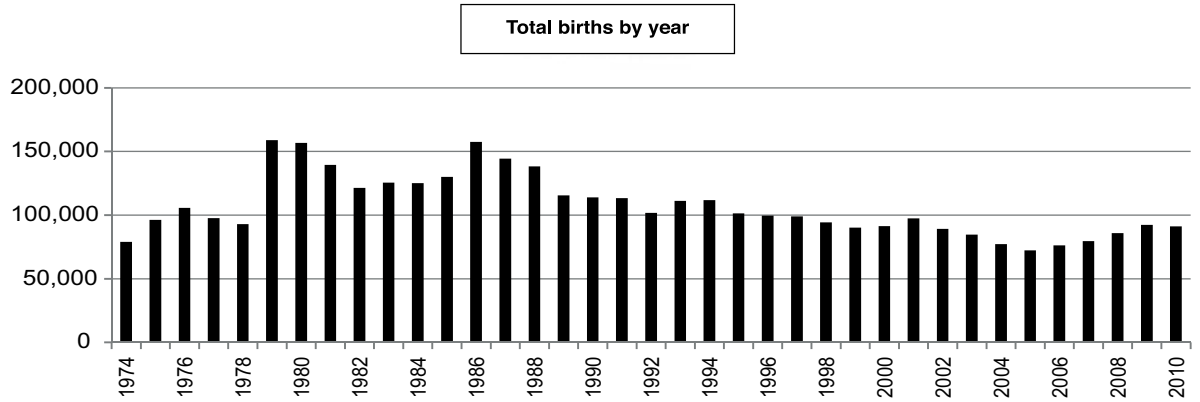
Sources of ascertainment:
Reports are obtained from delivery units and pediatric clinics of the participating hospitals.

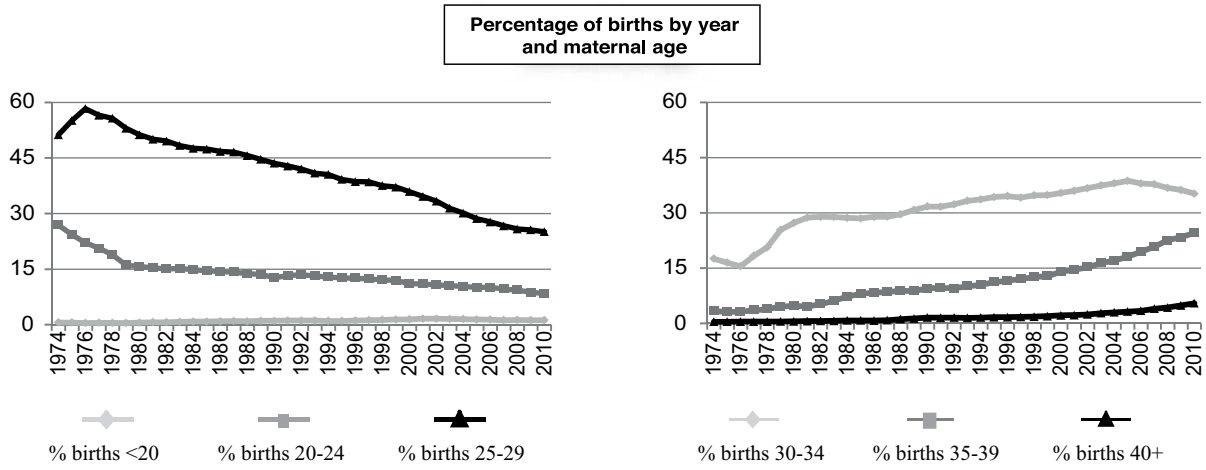
Exposure information:
Exposure to drugs, X-ray and viral infections are available.

Background information:
Basic epidemiological information on all births is available from each participating hospital.

Addresses and Staff:
Fumiki Hirahara, MD
Yokohama City University Hospital
Dept. OB V GYN
3-9 Fukuura, Kanazawaku
Yokohama, 236-0004, Japan
Phone: 81-45-787-2689
Fax: 81-45-787-2689
E-mail: hirafu@med.yokohama-cu.ac.jp

Japan: JAOG


Total births by year
200,000
150,000
100,000
50,000
0
1974
1976
1978
1980
1982
1984
1986
1988
1990
1992
1994
1996
1998
2000
2002
2004
2006
2008
2010


Percentage of births by year and maternal age
60
45
30
15
0
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Japan JAOG, 2010

Live births (LB)	90,444
Stillbirths (SB)	638
Total births	91,082
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	5	nr	0.88
Spina bifida	52	2	nr	5.93
Encephalocele	0	0	nr	0.00
Microcephaly	9	3	nr	1.32
Holoprosencephaly	8	4	nr	1.32
Hydrocephaly	64	5	nr	7.58
Anophthalmos	4	2	nr	0.66
Microphthalmos	3	0	nr	0.33
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	0	0	nr	0.00
Microtia	13	2	nr	1.65
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	52	3	nr	6.04
Tetralogy of Fallot	63	3	nr	7.25
Hypoplastic left heart syndrome	50	7	nr	6.26
Coarctation of aorta	69	2	nr	7.80
Choanal atresia, bilateral	1	0	nr	0.11
Cleft palate without cleft lip	71	2	nr	8.01
Cleft lip with or without cleft palate	187	9	nr	21.52
Oesophageal atresia/stenosis with or without fistula	37	11	nr	5.27
Small intestine atresia/stenosis	69	4	nr	8.01
Anorectal atresia/stenosis	54	6	nr	6.59
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	56	3	nr	6.48
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	27	3	nr	3.29
Cystic kidney	49	4	nr	5.82
Bladder exstrophy	4	0	nr	0.44
Polydactyly, preaxial	49	0	nr	5.38
Total Limb reduction defects (include unspecified)	37	4	nr	4.50
Transverse	3	0	nr	0.33
Preaxial	8	1	nr	0.99
Postaxial	2	0	nr	0.22
Intercalary	11	2	nr	1.43
Mixed	9	1	nr	1.10
Unspecified	4	0	nr	0.44
Diaphragmatic hernia	57	8	nr	7.14
Omphalocele	29	7	nr	3.95
Gastroschisis	22	2	nr	2.63
Unspecified Omphalocele/Gastroschisis	2	3	nr	0.55
Prune belly sequence	0	0	nr	0.00
Trisomy 13	13	6	nr	2.09
Trisomy 18	58	39	nr	10.65
Down syndrome, all ages (include age unknown)	124	8	nr	14.49
<20	2	0	nr	17.87
20-24	0	0	nr	0.00
25-29	12	1	nr	5.69
30-34	22	1	nr	7.17
35-39	54	5	nr	26.37
40+	34	1	nr	70.24
unknown	0	0	nr	---

nr = not reported

Japan: JAOG, Previous years rates 1974 - 2010

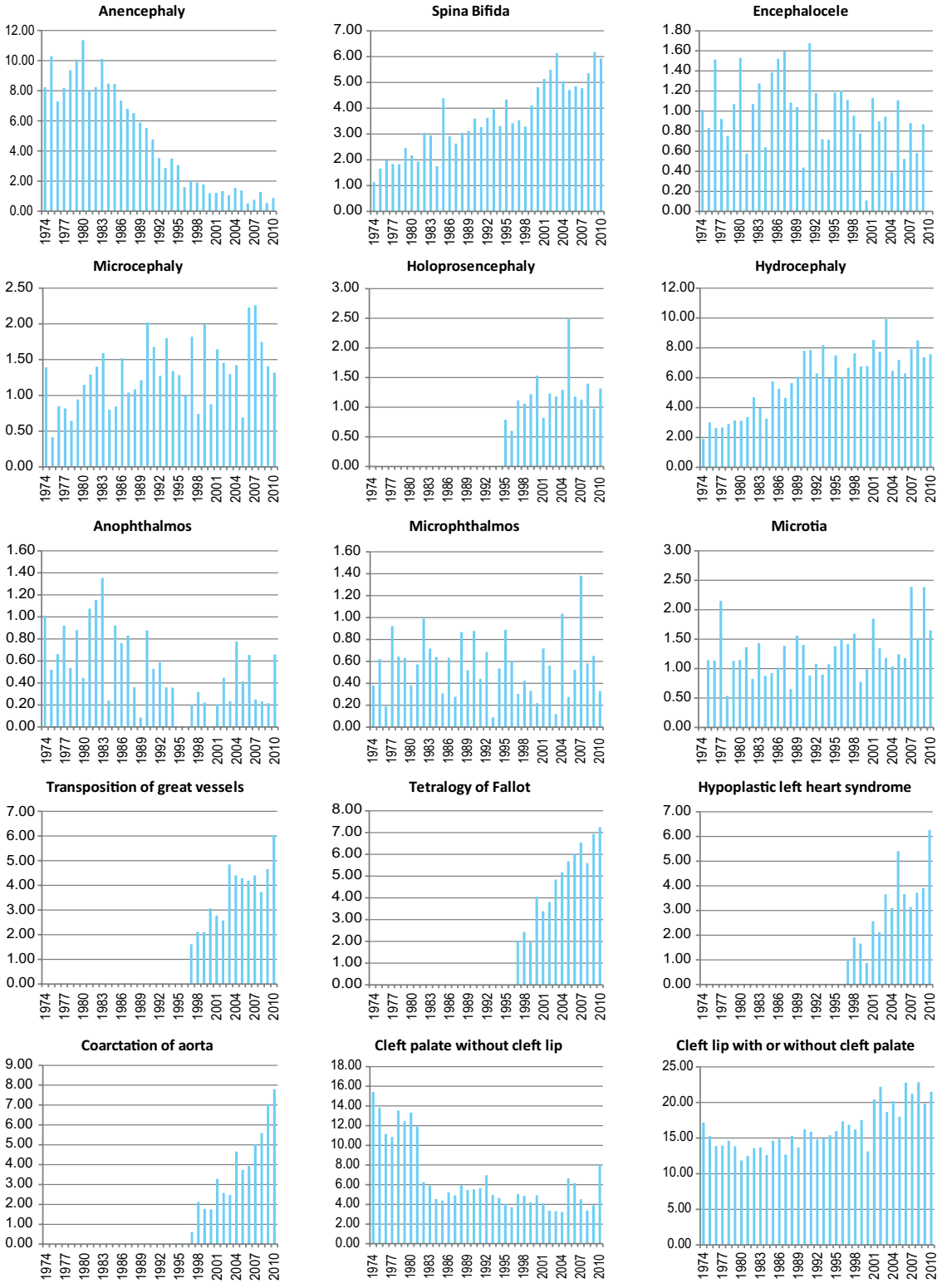
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**787,267**	**641,607**	**669,652**	**539,382**	**474,407**	**420,750**	**425,103**
Anencephaly	9.48	8.65	6.50	3.56	1.71	1.31	0.80
Spina bifida	1.96	2.81	3.03	3.69	3.82	5.32	5.46
Encephalocele	1.13	0.98	1.18	1.09	0.84	0.90	0.56
Microcephaly	0.90	1.18	1.36	1.48	1.29	1.33	1.76
Holoprosencephaly	nr	nr	nr	0.79*	1.10	1.35	1.20
Hydrocephaly	2.85	4.21	5.78	7.17	6.77	8.03	7.55
Anophthalmos	0.70	0.95	0.60	0.37	0.15	0.40	0.40
Microphthalmos	0.53	0.64	0.63	0.52	0.38	0.55	0.68
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00*
Anotia	nr	nr	nr	nr	nr	nr	0.00
Microtia	1.08	1.09	1.18	1.06	1.26	1.35	1.83
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	0.00*
Transposition of great vessels	nr	nr	nr	nr	2.21*	3.71	4.63
Tetralogy of Fallot	nr	nr	nr	nr	2.61*	4.49	6.49
Hypoplastic left heart syndrome	nr	nr	nr	nr	1.36*	3.28	4.19
Coarctation of aorta	nr	nr	nr	nr	1.55*	3.30	5.98
Choanal atresia, bilateral	nr	nr	nr	nr	nr	nr	0.02
Cleft palate without cleft lip	12.85	6.70	5.39	5.25	4.55	4.06	5.20
Cleft lip with or without cleft palate	14.07	13.39	14.52	15.41	16.25	19.99	21.59
Oesophageal atresia/stenosis with or without fistula	1.05*	1.22	1.64	2.35	2.87	5.04	4.49
Small intestine atresia/stenosis	nr	nr	nr	nr	4.43*	6.63	7.41
Anorectal atresia/stenosis	3.96	3.58	4.42	4.17	4.38	5.70	6.73
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	1.83	2.35	2.42	3.02	2.95	4.52	4.78
Epispadias	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr	nr	nr	nr
Renal agenesis	nr	nr	1.09	1.56	1.67	2.14	2.66
Cystic kidney	nr	nr	nr	nr	2.77*	4.80	4.12
Bladder exstrophy	0.18*	0.12	0.16	0.09	0.21	0.31	0.26
Polydactyly, preaxial	nr	nr	5.88	6.64	6.09	6.44	6.40
Total Limb reduction defects (include unspecified)	nr	nr	nr	3.30*	3.18	3.64	3.95
Transverse	nr	nr	nr	0.31*	0.36	0.40	0.26
Preaxial	nr	nr	nr	0.52*	0.57	0.67	0.87
Postaxial	nr	nr	nr	0.22*	0.34	0.33	0.40
Intercalary	nr	nr	nr	1.42*	0.95	0.81	1.01
Mixed	nr	nr	nr	0.52*	0.59	0.93	1.04
Unspecified	nr	nr	nr	0.31*	0.38	0.50	0.38
Diaphragmatic hernia	nr	nr	2.05*	3.08	4.43	6.01	6.14
Omphalocele	1.09	1.37	3.03	2.98	3.56	3.45	4.05
Gastroschisis	1.05	0.86	1.33	1.45	2.11	2.66	2.52
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.12	0.37	0.21	0.31	0.26
Prune belly sequence	nr	nr	nr	0.20*	0.00	0.02	0.09
Trisomy 13	nr	nr	nr	0.47*	0.95	1.50	2.00
Trisomy 18	nr	nr	nr	2.20*	4.01	8.03	9.39
Down syndrome, all ages (include age unknown)	4.26*	4.72	6.17	6.27	8.43	10.53	12.02
<20	nr	nr	nr	5.81*	1.64	6.13	5.58
20-24	nr	nr	nr	2.15*	2.98	4.05	3.07
25-29	nr	nr	nr	3.99*	5.39	5.45	5.31
30-34	nr	nr	nr	5.67*	8.02	8.87	8.20
35-39	nr	nr	nr	16.39*	18.78	21.37	22.18
40-44	nr	nr	nr	66.60*	47.53	56.67	47.61
45+	nr	nr	nr	nr	nr	nr	nr
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 7 or 5 years

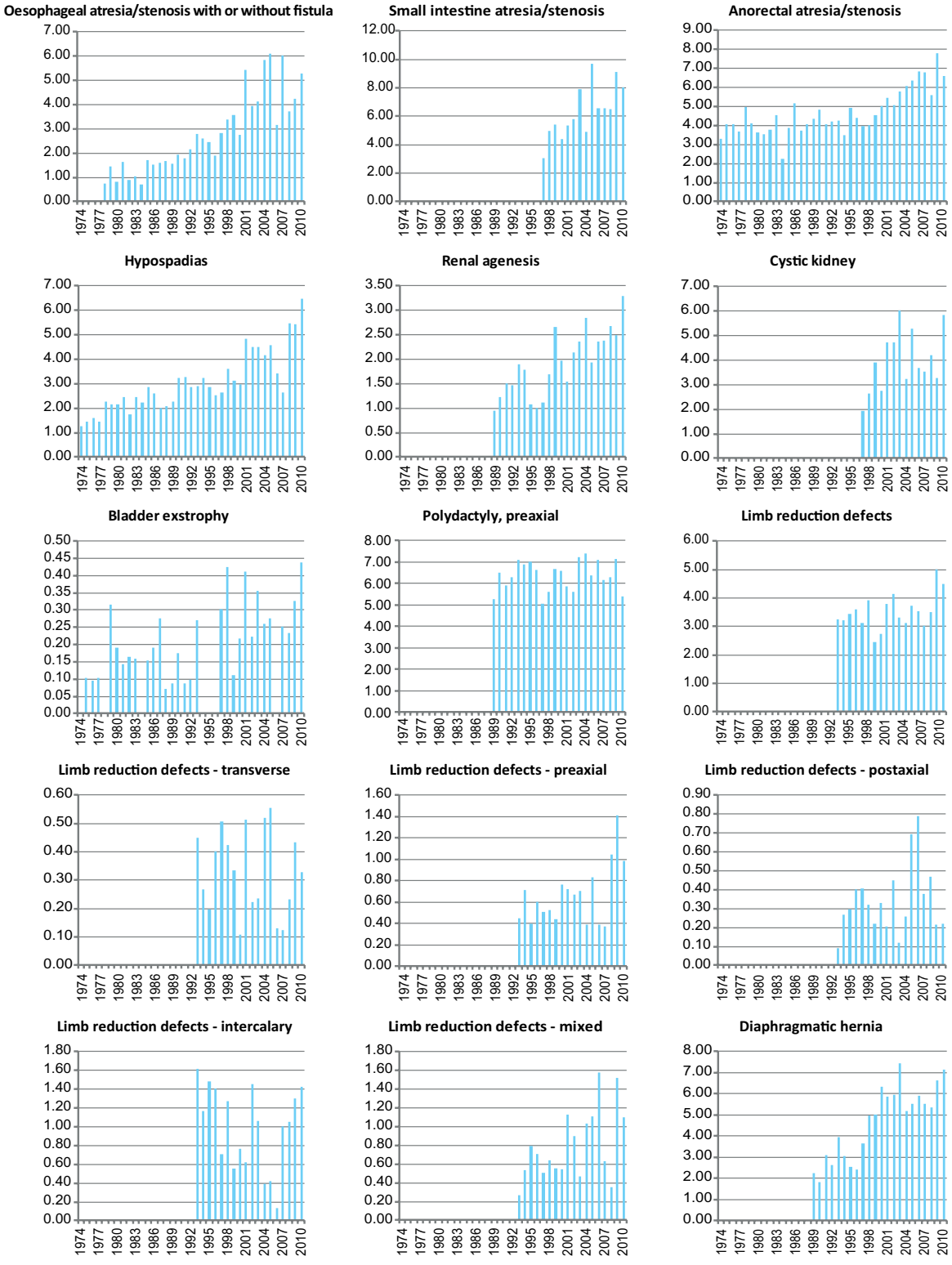
Japan: JAOG

Time trends 1974-2010 (Birth prevalence rates per 10,000)



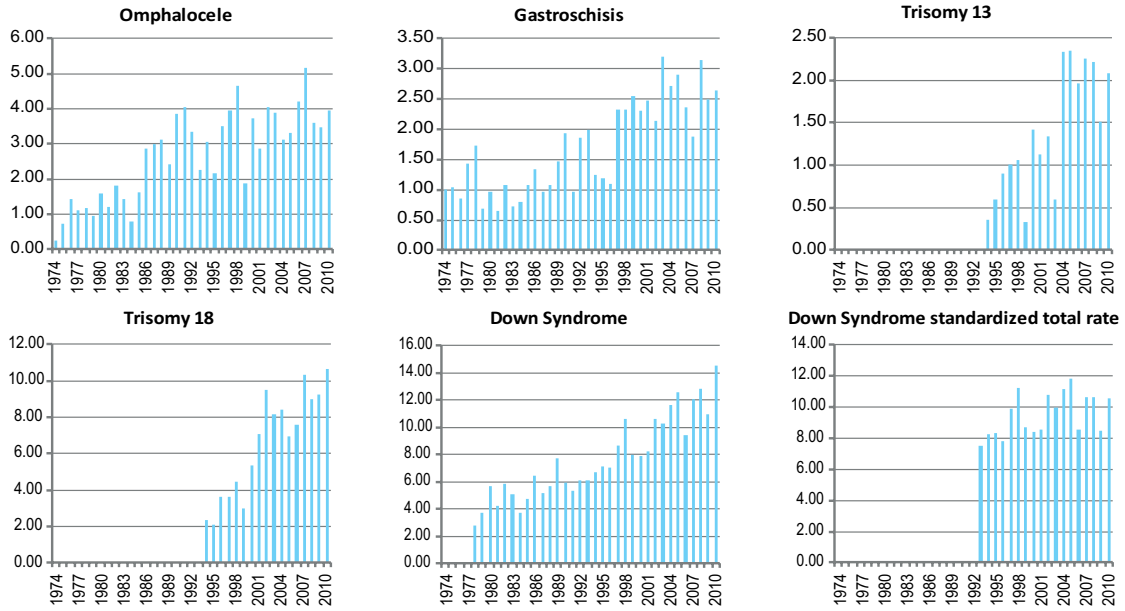
Note: L+S rates

Japan: JAOG



Note: L+S rates

Japan: JAOG



Note: L+S rates

Malta: MCAR
Malta Congenital Anomalies Register

History:
The register started in 1985 as a research project of the University of Malta. It started as a hospital based register collecting data regarding congenital anomalies diagnosed in babies born at the main general hospital. It became a member of EUROCAT in 1986. Funding for the research project was stopped in 1995 and in 1997 the Department of Health Information assumed the functions of data collection increasing coverage to all hospitals on the islands making it a population based register. The Register was accepted as an associate member of the Clearinghouse in 2000.

Size and coverage:
The registry is population based and now covers 4,000 births per year.

Legislation and funding:
The registry is run and funded by the state Department of Health Information and Research. Reporting is not statutory.

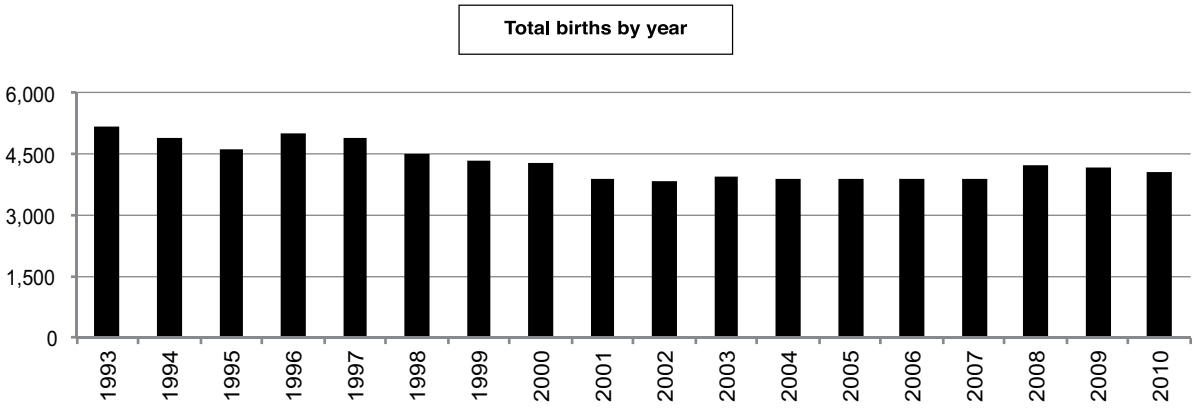
Sources of ascertainment:
The registry employs active data collection from multiple sources including delivery and obstetric wards, doctors' reporting, cardiac lab records, genetics clinic records, National Mortality Register, National Obstetric Information Systems database, Hospital Activity Analysis databases, National Cancer Register and the Hypothyroid Screening Programme.

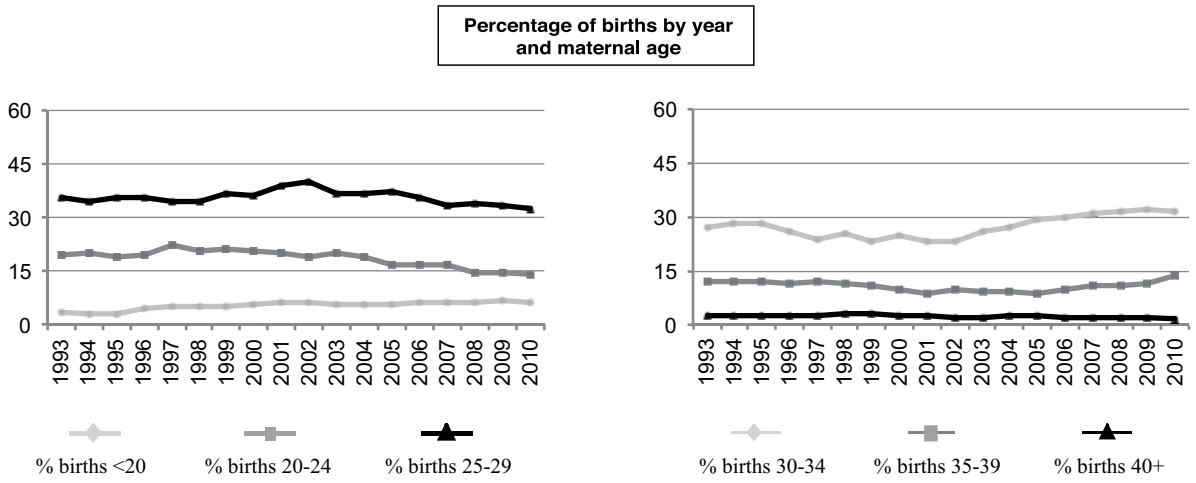
Exposure information:
Information regarding maternal exposure to medicinal drugs, smoking, alcohol and drug abuse as well as parental occupation are collected for all malformed infants and fetuses.

Background information:
Epidemiological background data on all births are available from the National Obstetric Information Systems database and vital statistics.

Addresses and Staff:
Miriam Gatt, MD, Programme Director
Malta Congenital Anomalies Registry
Department of Health Information and Research
95, Guardamangia Hill
Guardamangia PTA 1313, Malta
Phone: 356 25599000
Fax: 356 25599385
E-mail: miriam.gatt@gov.mt

Malta: MCAR


Total births by year
6,000
4,500
3,000
1,500
0
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010


Percentage of births by year and maternal age
60
45
30
15
0
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Malta: MCAR, 2010

Live births (LB)	4,018
Stillbirths (SB)	18
Total births	4,036
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0		2.48
Spina bifida	1	0		2.48
Encephalocele	2	0		4.96
Microcephaly	2	0		4.96
Holoprosencephaly	0	0		0.00
Hydrocephaly	0	0		0.00
Anophthalmos	0	0		0.00
Microphthalmos	1	0		2.48
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	0	0		0.00
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	0	0		0.00
Tetralogy of Fallot	0	0		0.00
Hypoplastic left heart syndrome	2	0		4.96
Coarctation of aorta	1	0		2.48
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	3	0		7.43
Cleft lip with or without cleft palate	5	0		12.39
Oesophageal atresia/stenosis with or without fistula	1	0		2.48
Small intestine atresia/stenosis	0	1		2.48
Anorectal atresia/stenosis	0	0		0.00
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	7	0		17.34
Epispadias	0	0		0.00
Indeterminate sex	0	0		0.00
Renal agenesis	0	0		0.00
Cystic kidney	1	0		2.48
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	4	0		9.91
Total Limb reduction defects (include unspecified)	3	0		7.43
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	nr	nr		nr
Diaphragmatic hernia	3	1		9.91
Omphalocele	0	0		0.00
Gastroschisis	0	0		0.00
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	0		2.48
Trisomy 18	1	0		2.48
Down syndrome, all ages (include age unknown)	8	2		24.78
<20	0	0		0.00
20-24	0	1		17.48
25-29	0	0		0.00
30-34	4	0		31.60
35-39	4	1		89.13
40-44	0	0		0.00
45+	0	0		0.00
unknown	0	0		---

nr = not reported

Malta: MCAR, Previous years rates 1993 - 2010

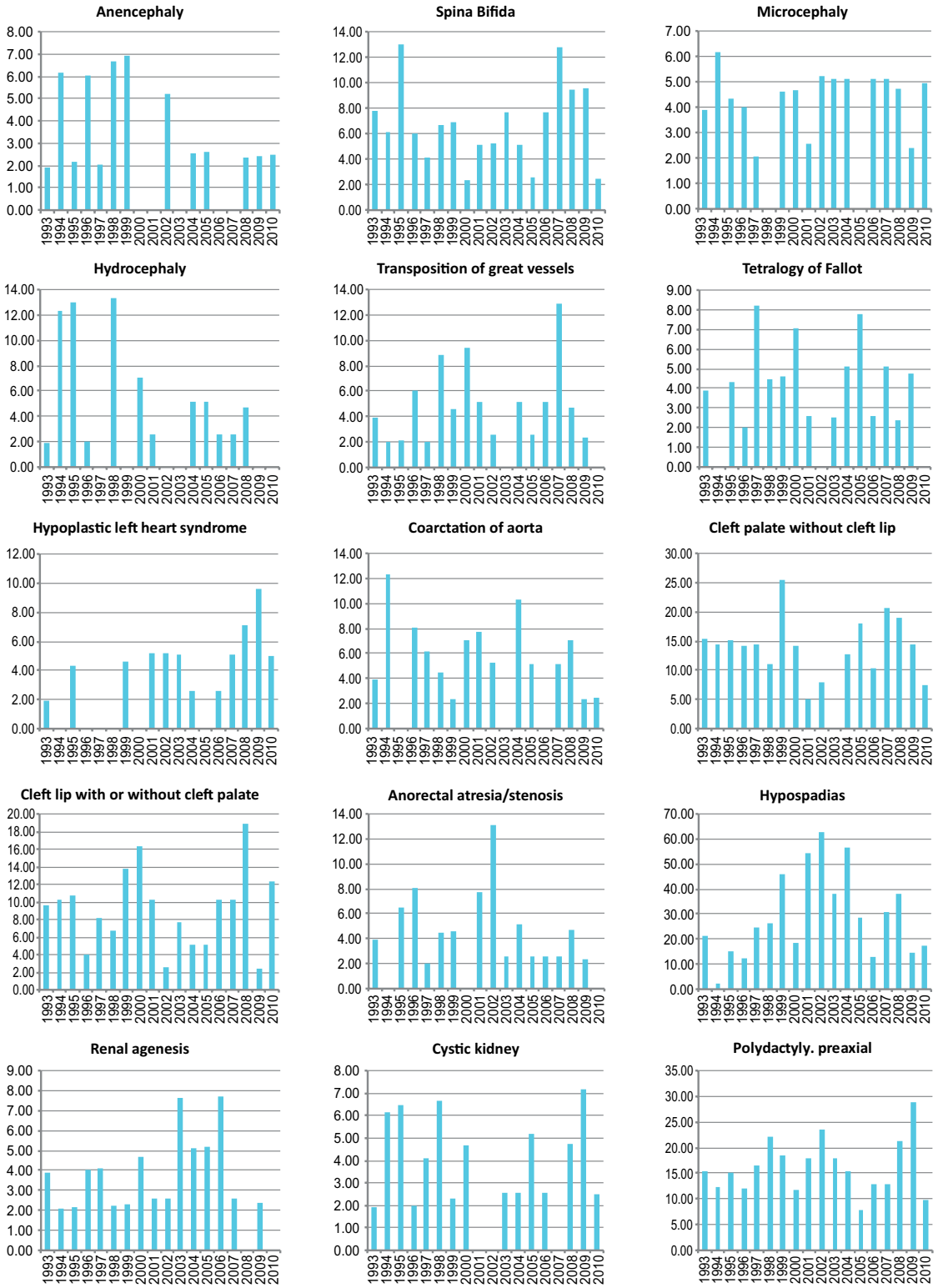
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995*	1996-2000	2001-2005	2006-2010
Total births				**14,668**	**22,964**	**19,396**	**20,233**
Anencephaly				3.41	4.35	2.06	1.48
Spina bifida				8.86	5.23	5.16	8.40
Encephalocele				1.36	2.61	2.06	1.98
Microcephaly				4.77	3.05	3.61	4.45
Holoprosencephaly				0.68	1.31	0.52	0.49
Hydrocephaly				8.86	4.35	2.58	1.98
Anophthalmos				0.68	0.00	0.00	0.00
Microphthalmos				0.00	2.18	0.52	0.49
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.00	0.00
Anotia				0.00	0.00	0.00	0.00
Microtia				0.00	0.00	0.00	0.00
Unspecified Anotia/Microtia				0.00	0.00	0.00	0.00
Transposition of great vessels				2.73	6.10	3.09	4.94
Tetralogy of Fallot				2.73	5.23	3.61	2.97
Hypoplastic left heart syndrome				2.05	0.87	3.61	5.93
Coarctation of aorta				5.45	5.66	5.67	3.46
Choanal atresia, bilateral				1.36	1.31	1.55	0.00
Cleft palate without cleft lip				15.00	15.68	8.76	14.33
Cleft lip with or without cleft palate				10.23	9.58	6.19	10.87
Oesophageal atresia/stenosis with or without fistula				1.36	2.18	1.55	2.47
Small intestine atresia/stenosis				0.68	1.74	2.06	1.98
Anorectal atresia/stenosis				3.41	3.92	6.19	2.47
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				12.95	25.26	47.95	22.74
Epispadias				2.05	0.44	0.00	0.00
Indeterminate sex				1.36	1.31	0.52	2.47
Renal agenesis				2.73	3.48	4.64	2.47
Cystic kidney				4.77	3.92	2.06	3.46
Bladder exstrophy				0.00	0.00	0.00	0.00
Polydactyly, preaxial				14.32	16.11	16.50	17.30
Total Limb reduction defects (include unspecified)				7.50	5.23	5.16	7.41
Transverse				nr	nr	nr	nr
Preaxial				nr	nr	nr	nr
Postaxial				nr	nr	nr	nr
Intercalary				nr	nr	nr	nr
Mixed				nr	nr	nr	nr
Unspecified				nr	nr	nr	nr
Diaphragmatic hernia				4.77	6.53	2.58	6.92
Omphalocele				2.73	1.74	2.06	3.46
Gastroschisis				1.36	0.87	1.03	0.49
Unspecified Omphalocele/Gastroschisis				0.00	0.00	0.00	0.00
Prune belly sequence				0.68	0.44	0.00	0.00
Trisomy 13				0.00	0.44	0.52	1.48
Trisomy 18				2.05	3.48	5.16	2.97
Down syndrome, all ages (include age unknown)				20.45	14.81	23.20	19.28
<20				0.00	16.75	0.00	15.41
20-24				0.00	0.00	2.72	6.44
25-29				5.83	4.92	8.14	4.39
30-34				22.24	14.17	26.03	17.50
35-39				68.81	42.60	84.70	56.60
40-44				166.21	132.01	238.10	159.15
45+				0.00	416.67	0.00	1,052.63
unknown				---	---	---	---

nr = not reported
* data include less than 5 years

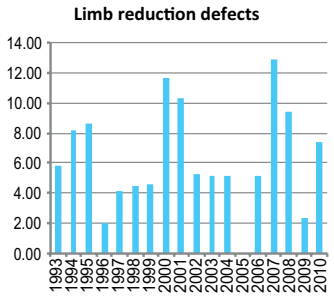
Malta: MCAR

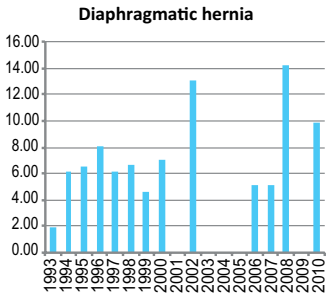
Time trends 1993-2010 (Birth prevalence rates per 10,000)

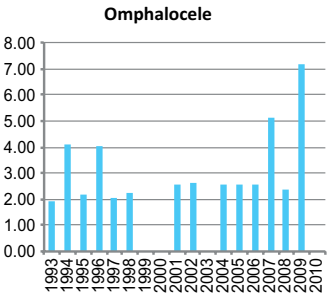


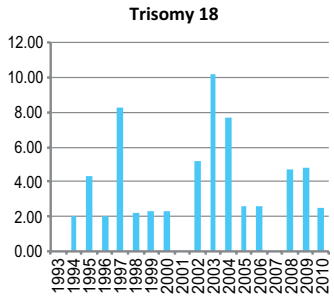
Note: L+S rates

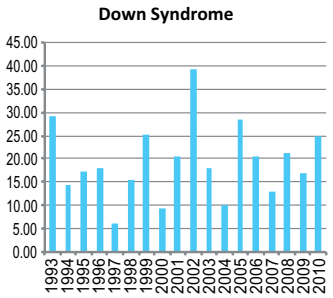
Malta: MCAR

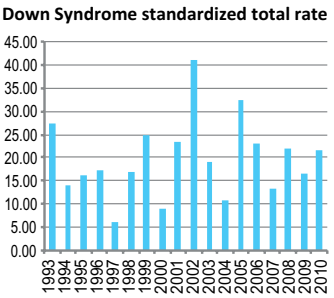












Note: L+S rates

Mexico: RYVEMCE

Mexican Registry and Epidemiological Surveillance of External Congenital Malformations

History:
The Programme was started in 1978. The Programme became a full member of the ICBDSR in 1980.

Size and coverage:
Reports are obtained from 21 hospitals in 11 cities in Mexico. Participation is voluntary. The annual number of births is approximately 62,000, about 3.5% of all births in Mexico. Stillbirths of 20 weeks or more gestation and/or at least 500g birthweight are included.

Legislation and funding:
The Programme is a research Programme and is funded by research grants.

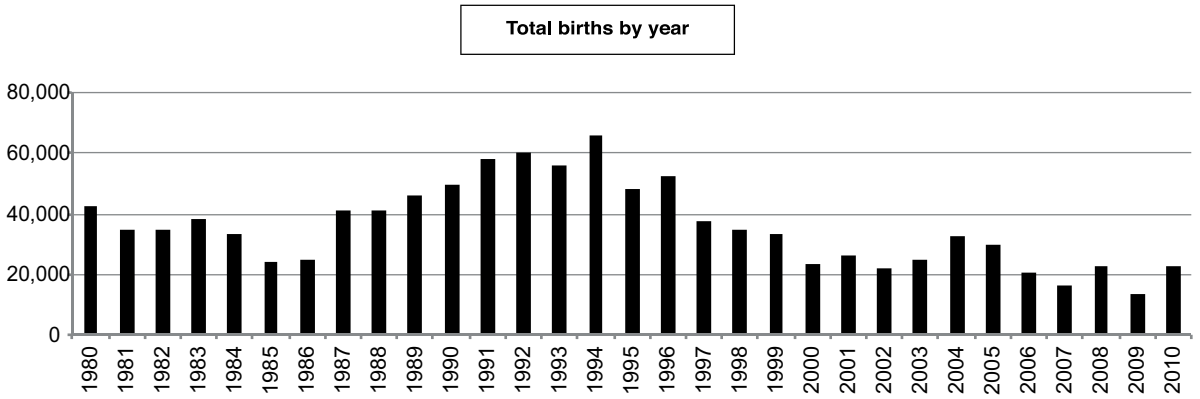
Sources of ascertainment:
Reports are obtained from the delivery units and pediatric departments of the participating hospitals.

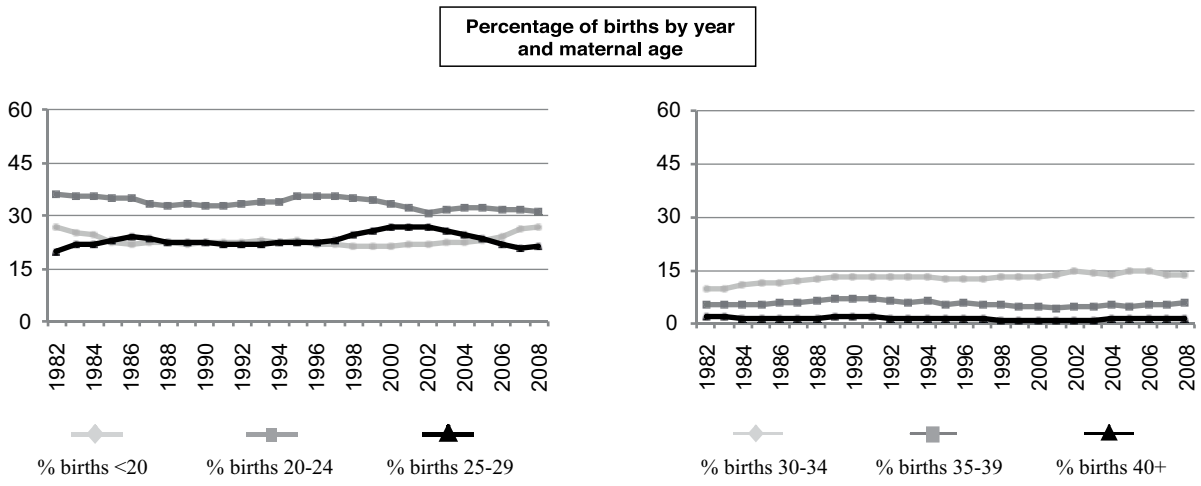
Exposure information:
The mother of each reported infant and the mother of a control infant-the next non-malformed infant born at that hospital with the same sex as the proband - are interviewed on various exposures, including drug usage and parental occupation.

Background information:
The total number of births in the hospitals is known.

Addresses and Staff:
Osvaldo Mutchinick, MD, Programme Director
RYVEMCE Departamento de Genética, Inst. Nacional de Ciencias Médicas y Nutrición
Vasco de Quiroga 15,Tlalpan, C.P.14000
Mexico DF, Mexico
Phone: 52-55-54870900 (ext 2514 and 2515)
Fax: 52-55-56556138
E-mail: osvaldo@servidor.unam.mx

Mexico: RYVEMCE





Mexico: RYVEMCE, 2010

Live births (LB)	22,115
Stillbirths (SB)	226
Total births	22,341
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	3		1.79
Spina bifida	7	1		3.58
Encephalocele	2	0		0.90
Microcephaly	5	1		2.69
Holoprosencephaly	4	1		2.24
Hydrocephaly	8	2		4.48
Anophthalmos	nr	nr		nr
Microphthalmos	nr	nr		nr
Unspecified Anophthalmos/Microphthalmos	3	0		1.34
Anotia	nr	nr		nr
Microtia	nr	nr		nr
Unspecified Anotia/Microtia	24	1		11.19
Transposition of great vessels	1	0		0.45
Tetralogy of Fallot	1	0		0.45
Hypoplastic left heart syndrome	1	0		0.45
Coarctation of aorta	2	0		0.90
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	3	0		1.34
Cleft lip with or without cleft palate	29	3		14.32
Oesophageal atresia/stenosis with or without fistula	9	0		4.03
Small intestine atresia/stenosis	5	0		2.24
Anorectal atresia/stenosis	5	0		2.24
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	3	0		1.34
Epispadias	0	0		0.00
Indeterminate sex	4	2		2.69
Renal agenesis	1	0		0.45
Cystic kidney	1	1		0.90
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	19	0		8.50
Total Limb reduction defects (include unspecified)	8	1		4.03
Transverse	4	0		1.79
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	1	0		0.45
Mixed	1	1		0.90
Unspecified	2	0		0.90
Diaphragmatic hernia	2	0		0.90
Omphalocele	5	0		2.24
Gastroschisis	14	1		6.71
Unspecified Omphalocele/Gastroschisis	nr	nr		nr
Prune belly sequence	0	0		0.00
Trisomy 13	2	0		0.90
Trisomy 18	1	0		0.45
Down syndrome, all ages (include age unknown)	30	2		14.32
<20	5	0		8.95
20-24	9	1		14.86
25-29	2	0		3.49
30-34	1	0		3.99
35-39	6	0		44.10
40+	7	1		186.20
unknown	0	0		---

nr = not reported

Mexico: RYVEMCE, Previous years rates 1980 - 2010

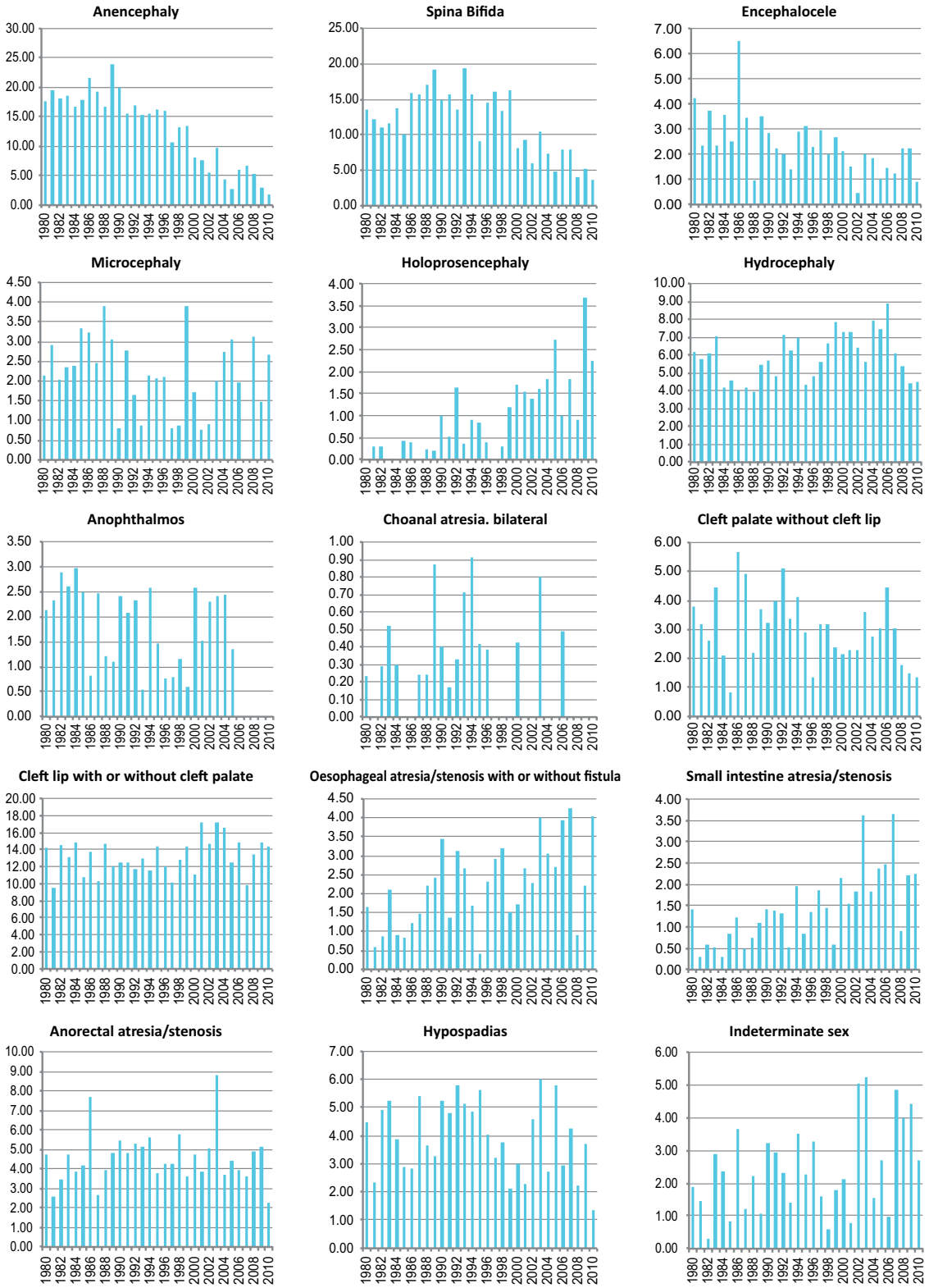
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**42,344**	**164,972**	**201,504**	**288,684**	**180,775**	**135,139**	**95,053**
Anencephaly	17.71	18.18	20.25	15.93	12.94	5.77	4.52
Spina bifida	13.46	11.76	16.62	14.86	14.11	7.47	5.58
Encephalocele	4.25	2.91	3.18	2.32	2.43	1.41	1.58
Microcephaly	2.13	2.55	2.58	1.91	1.88	2.00	2.00
Holoprosencephaly	0.00	0.18	0.40	0.87	0.61	1.85	1.79
Hydrocephaly	6.14	5.64	4.76	5.99	6.20	7.03	5.89
Anophthalmos	2.13	2.67	1.69	1.84	1.05	2.00	nr
Microphthalmos	nr	nr	nr	nr	nr	nr	nr
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	nr	nr	2.95
Anotia	nr	nr	nr	nr	nr	nr	nr
Microtia	nr	nr	nr	nr	nr	nr	nr
Unspecified Anotia/Microtia	7.79	6.61	6.30	6.58	6.47	9.40	10.10
Transposition of great vessels	0.00	0.06	0.10	0.17	0.28	0.30	0.74
Tetralogy of Fallot	0.00	0.00	0.00	0.28	0.11	0.15	0.32
Hypoplastic left heart syndrome	0.00	0.00	0.05	0.00	0.00	0.22	0.32
Coarctation of aorta	0.24	0.00	0.05	0.10	0.00	0.00	0.63
Choanal atresia, bilateral	0.24	0.24	0.40	0.52	0.17	0.15	0.11
Cleft palate without cleft lip	3.78	2.79	3.77	3.95	2.38	2.81	2.42
Cleft lip with or without cleft palate	14.17	12.67	12.56	12.51	12.11	15.61	13.47
Oesophageal atresia/stenosis with or without fistula	1.65	1.09	2.28	1.91	2.38	2.96	3.05
Small intestine atresia/stenosis	1.42	0.48	0.99	1.25	1.44	2.22	2.21
Anorectal atresia/stenosis	4.72	3.76	4.71	4.99	4.48	5.03	3.89
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	4.49	3.94	4.22	5.23	3.32	4.22	2.74
Epispadias	nr	nr	nr	nr	nr	0.16*	0.11
Indeterminate sex	1.89	1.64	2.18	2.53	1.99	2.89	3.26
Renal agenesis	0.71	0.24	0.50	0.62	0.50	0.52	1.26
Cystic kidney	0.24	0.30	0.55	0.87	1.00	1.70	0.84
Bladder exstrophy	0.47	0.48	0.40	0.38	0.61	0.15	0.00
Polydactyly, preaxial	10.39	11.88	14.14	12.68	11.40	13.54	8.52
Total Limb reduction defects (include unspecified)	5.20	6.12	6.90	5.96	5.09	6.96	5.37
Transverse	nr	nr	nr	nr	1.71*	3.85	2.63
Preaxial	nr	nr	nr	nr	0.86*	1.26	0.63
Postaxial	nr	nr	nr	nr	0.86*	0.44	0.21
Intercalary	nr	nr	nr	nr	0.43*	0.44	0.42
Mixed	nr	nr	nr	nr	0.86*	0.67	1.16
Unspecified	nr	nr	nr	nr	0.00*	0.30	0.32
Diaphragmatic hernia	0.94	0.42	1.09	0.97	0.89	1.41	0.95
Omphalocele	2.60	1.39	1.44	1.73	1.49	2.52	1.79
Gastroschisis	0.47	0.79	1.49	2.01	3.10	5.33	5.79
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	nr	nr
Prune belly sequence	0.94	1.21	1.29	0.80	0.94	0.59	0.11
Trisomy 13	0.71	0.18	0.30	0.21	0.11	0.22	1.16
Trisomy 18	1.18	0.61	0.55	0.31	0.06	0.30	0.95
Down syndrome, all ages (include age unknown)	14.41	11.88	14.24	14.06	11.56	11.03	13.15
<20	7.75	6.83	10.62	7.92	6.83	6.54	0.52
20-24	6.91	6.17	6.34	8.20	4.56	7.55	0.70
25-29	13.07	5.13	9.74	12.62	6.35	6.96	0.42
30-34	29.43	15.18	17.02	14.07	13.88	10.49	0.49
35-39	50.55	46.52	41.40	42.92	44.95	51.67	2.93
40-44	88.50	135.37	133.29	156.75	233.16	94.09	16.49
45+	75.76	188.68*	188.68*	160.51	176.99*	0.00*	303.03*
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

Mexico: RYVEMCE

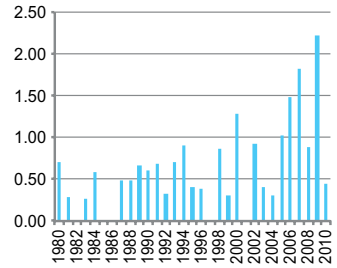
Time trends 1980-2010 (Birth prevalence rates per 10,000)



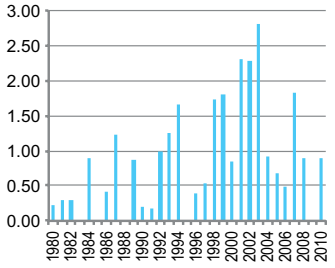
Note: L+S rates

Mexico: RYVEMCE

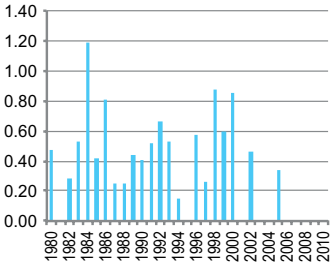
Renal agenesis



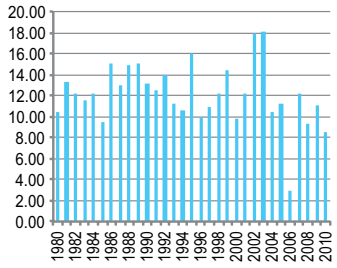
Cystic kidney



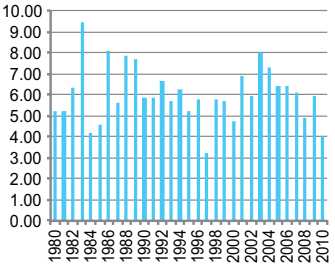
Bladder exstrophy



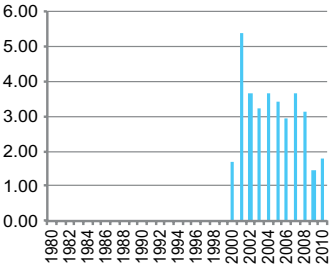
Polydactyly, preaxial



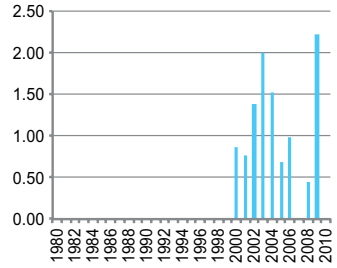
Limb reduction defects



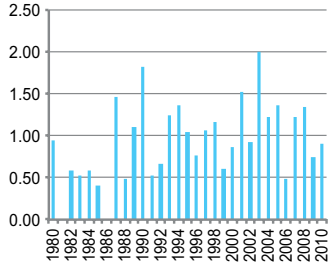
Limb reduction defects - transverse



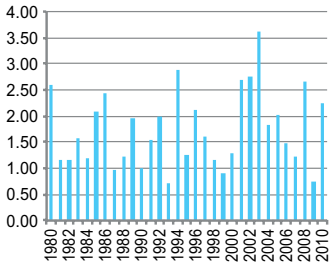
Limb reduction defects - preaxial



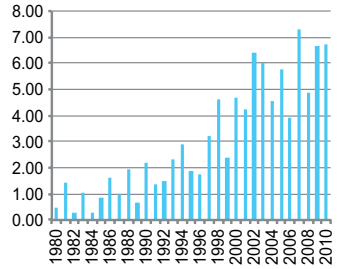
Diaphragmatic hernia



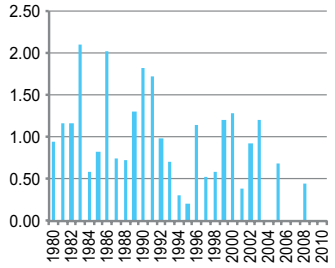
Omphalocele



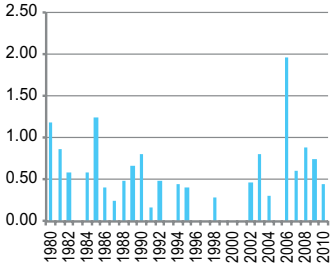
Gastroschisis



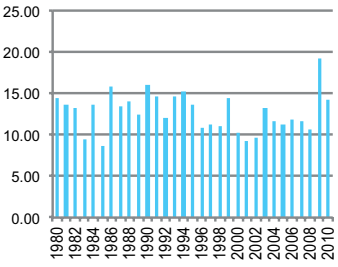
Prune belly sequence



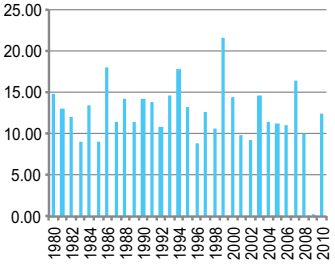
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

New Zealand
New Zealand Birth Defects Registry

History:
The Registry (previously the New Zealand Birth Defects Monitoring Programme) began in 1975 and became a full member of the ICBDSR in 1979.

Size and coverage:
The Registry covers all livebirths (approximately 60,000 per year) delivered or treated in a New Zealand publicly funded hospital. Only these data are included in annual reports to the ICBDSR. Data on fetal deaths are included in the database together with additional cases derived from the national perinatal and mortality databases. In late 1995 the definition of fetal death stillbirth was changed from 28 weeks completed gestation to 20 weeks or more gestation and/or 400g birthweight. A voluntary system for the registration of birth defects in terminations of pregnancy was implemented in 2011, but other options for ascertainment are currently being explored.

Legislation and funding:
The NZBDR is operated by Centre for Public Health Research, Massey University, with funding from the Ministry of Health.

Sources of ascertainment:
Ascertainment is from discharge records of publicly funded hospitals, fetal death notification forms, and terminations of pregnancy.

Exposure information:
Limited exposure information are currently available.

Background information:
General epidemiological characteristics for all births are available.

Addresses and Staff:
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Director
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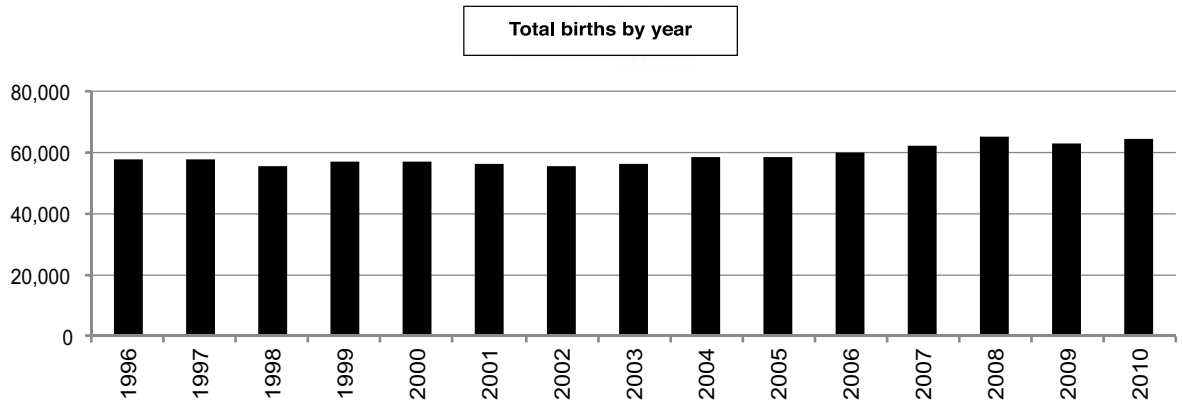
Massey University
PO Box 756
Wellington 6140
New Zealand
Tel: +64-4-801-4985
Fax: +64-4-380-0600
Email: b.borman@massey.ac.nz

New Zealand


Total births by year
80,000
60,000
40,000
20,000
0
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010

New Zealand, 2010

Live births (LB)	63,897
Stillbirths (SB)	418
Total births	64,315
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	nr	nr	0.31
Spina bifida	9	nr	nr	1.40
Encephalocele	5	nr	nr	0.78
Microcephaly	16	nr	nr	2.49
Holoprosencephaly	0	nr	nr	0.00
Hydrocephaly	27	nr	nr	4.20
Anophthalmos	0	nr	nr	0.00
Microphthalmos	2	nr	nr	0.31
Unspecified Anophthalmos/Microphthalmos	0	nr	nr	0.00
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	43	nr	nr	6.69
Tetralogy of Fallot	25	nr	nr	3.89
Hypoplastic left heart syndrome	10	nr	nr	1.55
Coarctation of aorta	13	nr	nr	2.02
Choanal atresia, bilateral	5	nr	nr	0.78
Cleft palate without cleft lip	53	nr	nr	8.24
Cleft lip with or without cleft palate	27	nr	nr	4.20
Oesophageal atresia/stenosis with or without fistula	10	nr	nr	1.55
Small intestine atresia/stenosis	8	nr	nr	1.24
Anorectal atresia/stenosis	8	nr	nr	1.24
Undescended testis (36 weeks of gestation or later)	283	nr	nr	44.00
Hypospadias	127	nr	nr	19.75
Epispadias	nr	nr	nr	nr
Indeterminate sex	6	nr	nr	0.93
Renal agenesis	18	nr	nr	2.80
Cystic kidney	30	nr	nr	4.66
Bladder exstrophy	3	nr	nr	0.47
Polydactyly, preaxial	59	nr	nr	9.17
Total Limb reduction defects (include unspecified)	8	nr	nr	1.24
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	16	nr	nr	2.49
Omphalocele	38	nr	nr	5.91
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	2	nr	nr	0.31
Trisomy 18	5	nr	nr	0.78
Down syndrome, all ages (include age unknown)	51	nr	nr	7.93
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported

New Zealand, Previous years rates 1980 - 2010

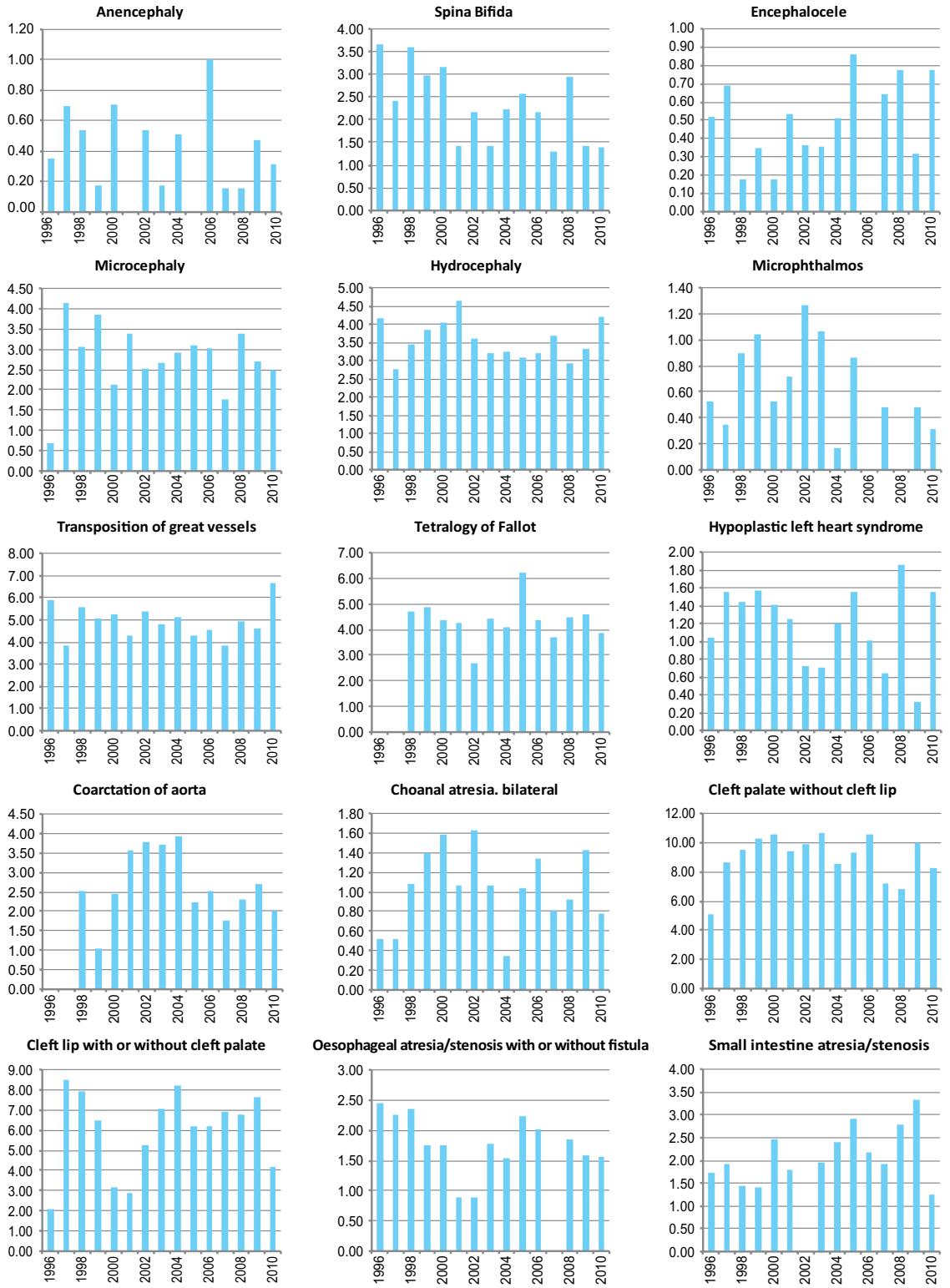
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**46,180**	**249,914**	**279,760**	**293,819**	**284,949**	**284,803**	**314,017**
Anencephaly	6.93	4.56	2.14	0.75	0.49	0.25	0.41
Spina bifida	12.56	10.08	5.72	3.98	3.16	1.97	1.85
Encephalocele	nr	0.66*	0.74*	0.00*	0.39	0.53	0.51
Microcephaly	nr	nr	nr	nr	2.77	2.91	2.68
Holoprosencephaly	nr	nr	nr	nr	nr	nr	nr
Hydrocephaly	7.36	3.48	3.36	2.76	3.65	3.55	3.47
Anophthalmos	nr	nr	nr	nr	0.00	0.07	0.12*
Microphthalmos	nr	nr	nr	nr	0.67	0.81	0.31*
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	0.00	0.00	0.24*
Anotia	nr	nr	nr	nr	nr	nr	nr
Microtia	nr	nr	nr	nr	nr	nr	nr
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	nr	nr	0.55*	nr	5.12	4.78	4.94
Tetralogy of Fallot	nr	nr	nr	nr	4.65*	4.35	4.20
Hypoplastic left heart syndrome	nr	nr	0.82*	1.90*	1.40	1.09	1.08
Coarctation of aorta	nr	nr	nr	nr	2.00*	3.44	2.26
Choanal atresia, bilateral	nr	nr	nr	nr	1.02	1.02	1.05
Cleft palate without cleft lip	6.06	6.44	7.11	5.04	8.81	9.55	8.53
Cleft lip with or without cleft palate	10.83	8.56	7.58	3.57	5.62	5.93	6.34
Oesophageal atresia/stenosis with or without fistula	1.73	1.88	1.75	2.42	2.11	1.47	1.75*
Small intestine atresia/stenosis	nr	nr	nr	nr	1.79	2.27*	2.29
Anorectal atresia/stenosis	1.73	2.52	2.36	2.89	2.28	2.42	2.07
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	67.12*	73.24	52.07
Hypospadias	12.13	13.64	12.47	12.15*	22.53	28.69	25.19
Epispadias	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr	0.48*	0.81	0.80
Renal agenesis	nr	0.20*	0.43*	nr	3.52*	3.05	2.71
Cystic kidney	nr	nr	nr	nr	5.83	5.97	5.25
Bladder exstrophy	nr	nr	nr	nr	0.39*	0.25	0.13
Polydactyly, preaxial	nr	nr	nr	nr	5.99*	9.73	15.19
Total Limb reduction defects (include unspecified)	3.03	4.00	2.97	2.04	2.63	2.88	2.53*
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	2.01*
Diaphragmatic hernia	nr	1.51*	1.48*	nr	2.41*	2.46	2.56*
Omphalocele	nr	2.28	1.57	2.58*	nr	nr	4.85*
Gastroschisis	nr	0.28	0.62*	nr	nr	nr	1.11*
Unspecified Omphalocele/Gastroschisis	nr	0.00	0.49*	nr	nr	5.51*	2.69*
Prune belly sequence	nr	nr	nr	nr	nr	nr	nr
Trisomy 13	nr	nr	nr	nr	0.42	0.42	0.51
Trisomy 18	nr	nr	nr	nr	0.95	1.19	1.05
Down syndrome, all ages (include age unknown)	8.01	9.32	9.29	9.38*	11.02	11.31	9.11
<20	1.63	6.22	6.64*	nr	nr	nr	nr
20-24	4.52	4.55	3.14*	nr	nr	nr	nr
25-29	8.92	8.36	8.83*	nr	nr	nr	nr
30-34	10.46	9.92	8.38*	nr	nr	nr	nr
35-39	22.27	37.78	26.30*	nr	nr	nr	nr
40-44	82.42	97.04	274.46*	nr	nr	nr	nr
45+	0.00	144.93	217.39*	nr	nr	nr	nr
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

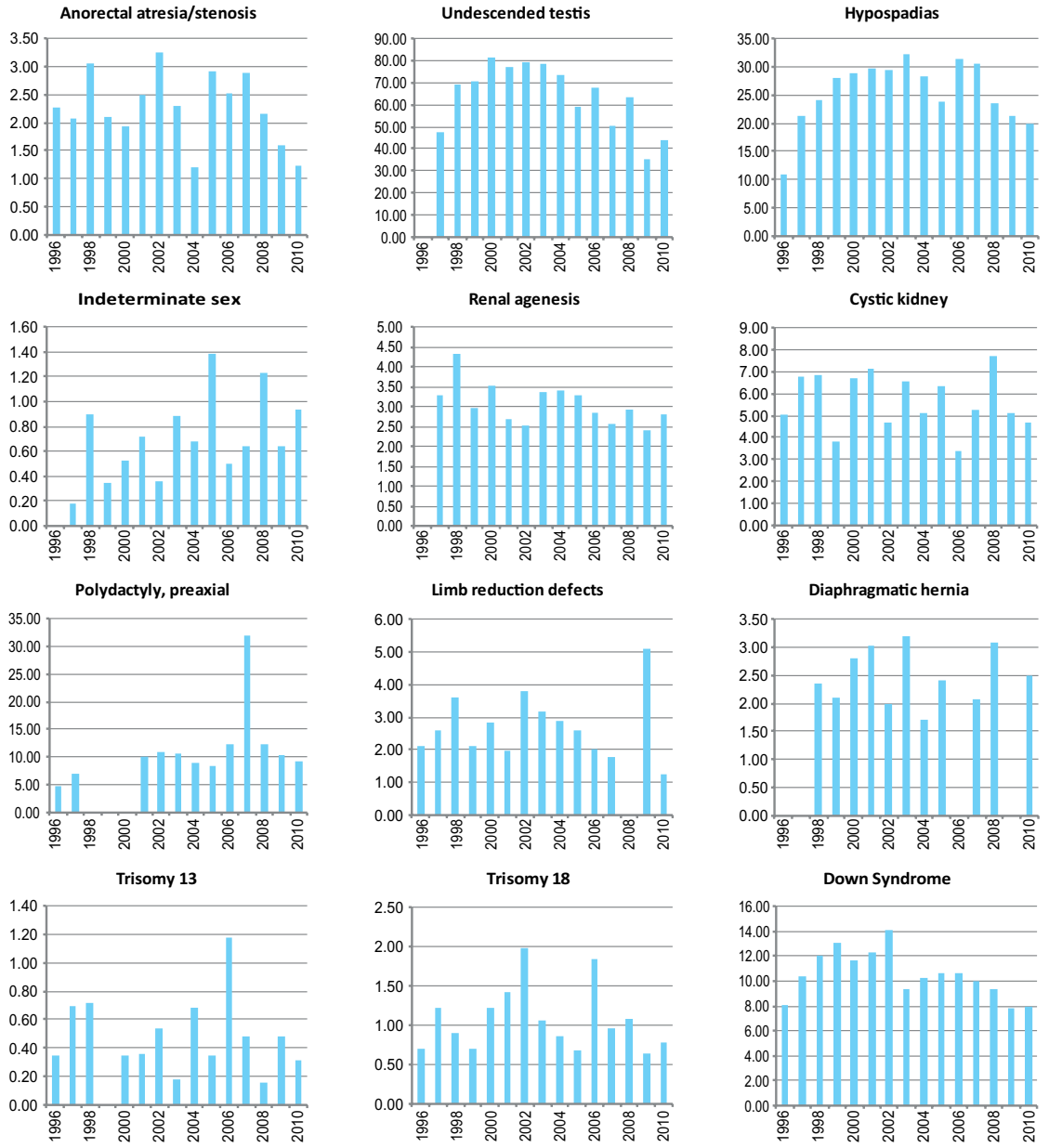
New Zealand

Time trends 1996-2010 (Birth prevalence rates per 10,000)



Note: L+S rates

New Zealand



Note: L+S rates

Northern Netherlands

EUROCAT Registration Northern Netherlands

History:
The Programme started in 1981, and became a Clearinghouse member in 1993.

Size and coverage:
In the beginning the Programme covered 7,500 births annually in the province of Groningen and northern Drenthe. Coverage was gradually increased to 20,000 births annually in the provinces Groningen, Friesland and Drenthe from 1989 onwards (10% of the Netherlands). Home deliveries (35% of births) are included.

Legislation and funding:
The Programme is funded by the Dutch Ministry of Public Health, Welfare and Sports. The registry is carried out in the Department of Genetics of the University Medical Center Groningen of the University of Groningen.

Sources of ascertainment:
Children and foetuses with congenital anomalies are reported on a voluntary basis by various sources: obstetricians, pediatricians, clinical geneticists, surgeons, general practitioners, midwives, well-baby clinics, pathologists and the national obstetric registry. Registry personnel is also actively involved in data collection. Children and foetuses with congenital anomalies diagnosed before or after birth are eligible for registration at the EUROCAT registry, if the mother lived in the region at the time of birth and the child has not reached the age of 10 at notification. There is no lower limit for gestational age. Spontaneous and induced abortions are included. A number of frequently occurring mild anomalies is not registered, unless they occur in combination with other congenital anomalies. Informed consent of the parents is needed.

Exposure information:
Since 1997 parents are asked to fill out a questionnaire including questions on occupational activities and medication use. Besides, pharmacy data are collected routinely and the actual use of the reported medications is verified with the mother.

Background information:
General statistics are available from the Dutch Central Bureau of Statistics (CBS).

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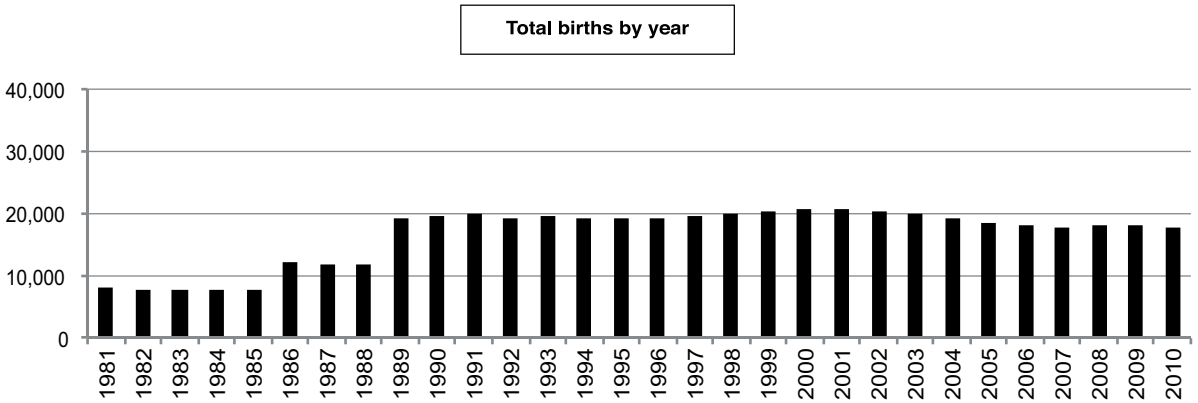
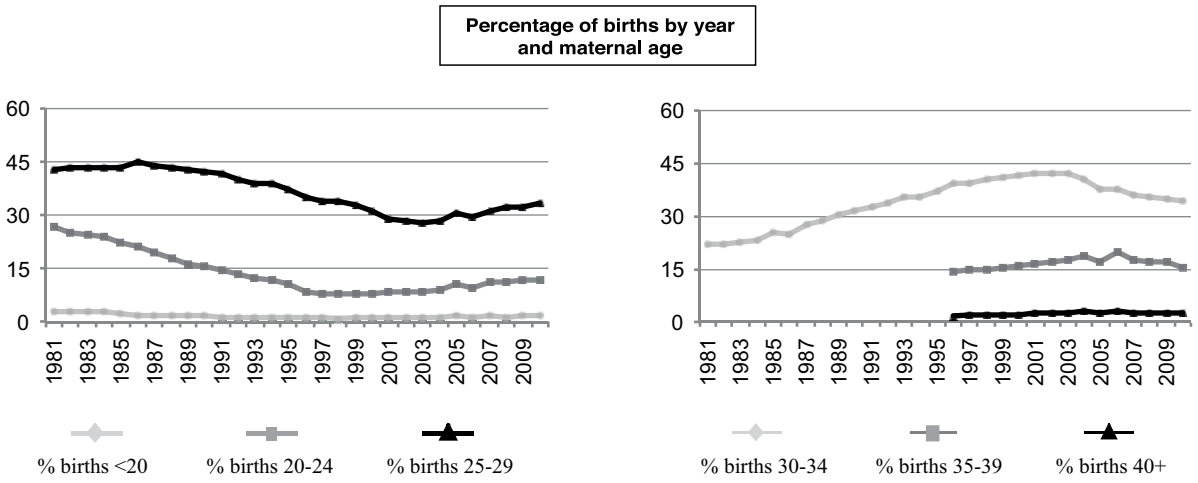
Northern Netherlands





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	18	90.0	Cystic kidney	17	40.5
Spina bifida	16	61.5	Limb reduction defects	10	27.8
Encephalocele	5	83.3	Diaphragmatic hernia	3	25.0
Holoprosencephaly	3	60.0	Omphalocele	6	42.9
Hydrocephaly	19	65.5	Gastroschisis	6	54.5
Hypoplastic left heart syndrome	15	55.6	Trisomy 13	7	58.3
Cleft palate without cleft lip	3	7.0	Trisomy 18	39	84.8
Cleft lip with or without cleft palate	5	8.3	Down syndrome	47	46.1
Renal agenesis	13	38.2			

Total ToPs with births defects = 249 (Ratio ToPs/Births: 4.64 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Northern Netherlands, 2010

Live births (LB)	17,494
Stillbirths (SB)	75
Total births	17,569
Number of terminations of pregnancy (ToP) for birth defects	101

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	6	4.55
Spina bifida	4	0	6	5.69
Encephalocele	1	0	1	1.14
Microcephaly	4	0	0	2.28
Holoprosencephaly	0	0	2	1.14
Hydrocephaly	6	0	6	6.83
Anophthalmos	0	0	1	0.57
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	3	0	1	2.28
Microtia	1	0	0	0.57
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	12	0	0	6.83
Tetralogy of Fallot	7	0	1	4.55
Hypoplastic left heart syndrome	6	2	8	9.11
Coarctation of aorta	5	0	0	2.85
Choanal atresia, bilateral	4	0	0	2.28
Cleft palate without cleft lip	12	0	1	7.40
Cleft lip with or without cleft palate	18	0	3	11.95
Oesophageal atresia/stenosis with or without fistula	3	0	1	2.28
Small intestine atresia/stenosis	1	0	2	1.71
Anorectal atresia/stenosis	6	0	4	5.69
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	39	0	0	22.20
Epispadias	1	0	0	0.57
Indeterminate sex	1	0	0	0.57
Renal agenesis	5	1	2	4.55
Cystic kidney	8	0	4	6.83
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	3	0	0	1.71
Total Limb reduction defects (include unspecified)	14	0	4	10.25
Transverse	9	0	3	6.83
Preaxial	1	0	1	1.14
Postaxial	6	0	3	5.12
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	3	0	0	1.71
Omphalocele	4	0	2	3.42
Gastroschisis	0	0	2	1.14
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	4	3.42
Trisomy 18	2	1	15	10.25
Down syndrome, all ages (include age unknown)	18	3	18	22.20
<20	0	0	0	0.00
20-24	1	0	0	4.81
25-29	2	1	2	8.48
30-34	4	0	5	14.90
35-39	10	2	7	69.14
40-44	1	0	4	108.70
45+	0	0	0	0.00
unknown	0	0	0	---

nr = not reported

Northern Netherlands, Previous years rates 1981 - 2010

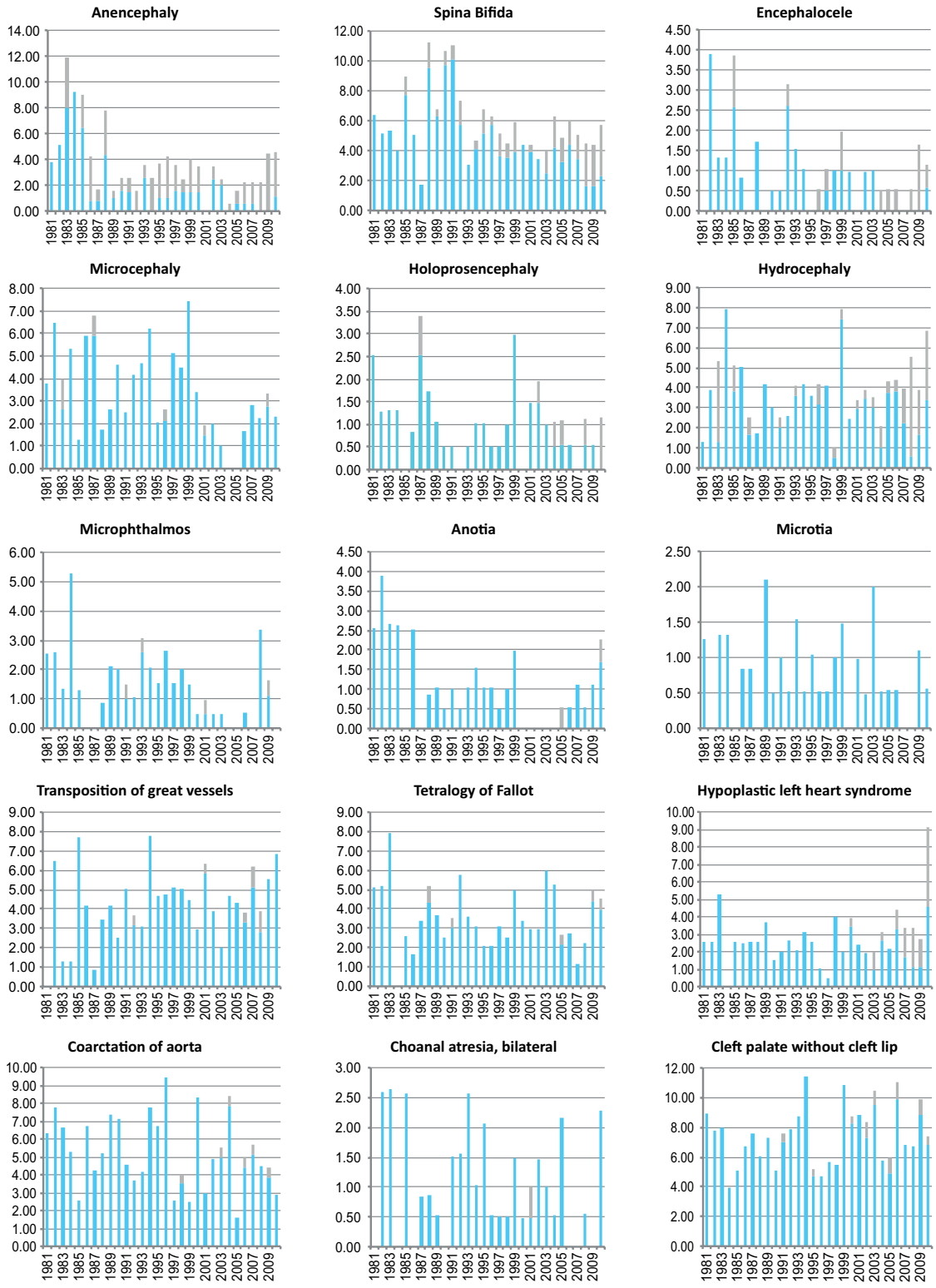
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births		**38,501**	**74,106**	**96,959**	**99,168**	**98,579**	**89,497**
Anencephaly		7.79	3.24	2.78	3.53	1.62	3.13
Spina bifida		5.97	7.42	6.60	5.24	4.56	5.14
Encephalocele		2.08	0.54	1.24	1.11	0.61	0.78
Microcephaly		4.16	4.18	3.92	4.64	1.01	2.46
Holoprosencephaly		1.30	1.35	0.62	1.01	1.32	0.67
Hydrocephaly		4.68	3.37	3.40	3.93	3.45	4.92
Anophthalmos		0.00	0.27	0.41	0.10	0.00	0.11
Microphthalmos		2.60	1.21	1.86	1.61	0.41	1.12
Unspecified Anophthalmos/Microphthalmos		nr	nr	nr	0.98*	1.28*	nr
Anotia		2.34	0.94	1.03	0.91	0.10	1.12
Microtia		0.78	0.94	0.93	0.71	0.91	0.45
Unspecified Anotia/Microtia		nr	nr	nr	nr	nr	nr
Transposition of great vessels		3.38	3.10	4.85	4.44	4.26	5.25
Tetralogy of Fallot		4.16	3.24	3.61	3.23	3.96	3.13
Hypoplastic left heart syndrome		2.60	2.56	2.48	2.32	2.33	4.58
Coarctation of aorta		5.71	6.34	5.36	5.34	4.67	4.47
Choanal atresia, bilateral		1.56	0.40	1.75	0.71	1.22	0.56
Cleft palate without cleft lip		6.75	6.48	8.15	7.16	7.91	8.38
Cleft lip with or without cleft palate		16.88	15.25	15.57	13.41	14.51	12.74
Oesophageal atresia/stenosis with or without fistula		2.60	2.70	2.99	4.03	3.65	2.23
Small intestine atresia/stenosis		2.60	2.97	2.68	2.42	1.52	2.01
Anorectal atresia/stenosis		2.34	3.78	2.78	4.13	3.14	4.47
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr
Hypospadias		16.62	9.58	9.90	15.93	19.78	21.34
Epispadias		0.26	0.67	0.52	0.40	0.61	0.67
Indeterminate sex		0.00	0.27	0.21	0.50	0.51	0.78
Renal agenesis		3.64	4.32	4.43	4.64	4.97	5.59
Cystic kidney		2.08	5.80	4.95	4.03	4.67	6.93
Bladder exstrophy		0.26	0.27	0.10	0.20	0.41	0.45
Polydactyly, preaxial		2.60	1.75	1.86	2.52	1.01	0.67
Total Limb reduction defects (include unspecified)		8.83	5.13	7.43	5.34	6.70	6.15
Transverse		5.45	2.83	3.82	3.23	4.36	4.47
Preaxial		1.82	0.54	1.03	0.71	0.91	1.12
Postaxial		0.78	0.67	2.06	0.91	0.10	1.68
Intercalary		0.26	0.00	0.31	0.10	0.20	0.22
Mixed		0.52	0.13	0.52	0.20	0.30	0.34
Unspecified		nr	nr	nr	nr	nr	nr
Diaphragmatic hernia		2.34	2.97	2.17	3.23	2.84	1.90
Omphalocele		1.56	2.43	3.30	2.22	2.03	2.35
Gastroschisis		0.78	0.81	0.41	1.01	1.01	1.45
Unspecified Omphalocele/Gastroschisis		nr	nr	nr	nr	nr	nr
Prune belly sequence		0.26	0.27	0.62	0.20	0.30	0.22
Trisomy 13		0.52	1.21	1.44	0.91	1.32	2.23
Trisomy 18		2.08	2.56	1.65	3.73	5.27	7.60
Down syndrome, all ages (include age unknown)		12.21	13.76	14.23	15.63	16.64	17.99
<20		0.00	0.00	0.00	0.00	0.00	0.00
20-24		10.62	4.56	10.59	3.76	5.61	6.02
25-29		6.60	13.14	4.72	9.09	9.16	7.41
30-34		14.65	7.44	15.97	10.73	10.66	16.67
35-39		40.21	45.45	33.26	39.28	32.86	40.46
40-44		nr	nr	nr	98.60	130.99	61.38
45+		nr	nr	nr	153.85	129.87	625.00
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

Northern Netherlands

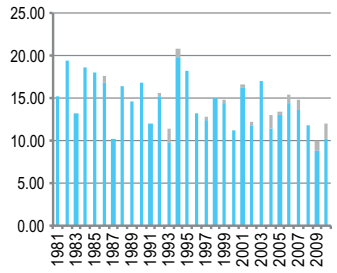
Time trends 1981-2010 (Birth prevalence rates per 10,000)



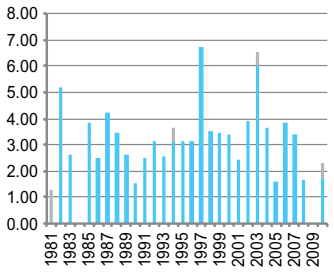
Note: L+S rates, ToP rates

Northern Netherlands

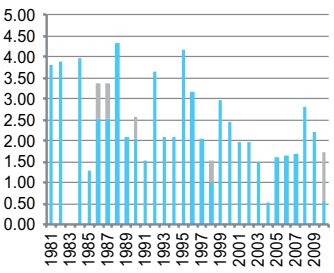
Cleft lip with or without cleft palate



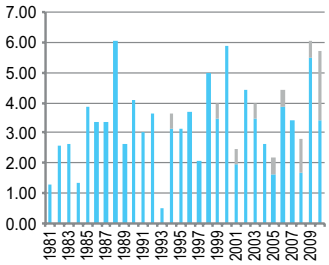
Oesophageal atresia/stenosis with or without fistula



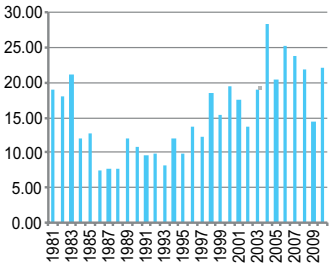
Small intestine atresia/stenosis



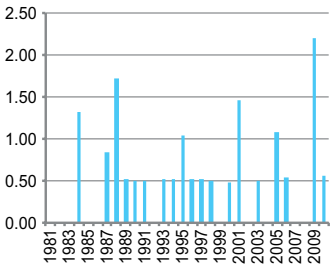
Anorectal atresia/stenosis



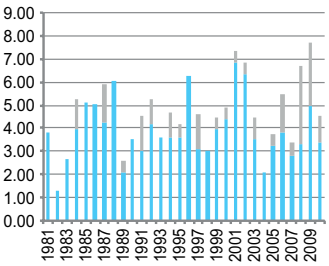
Hypospadias



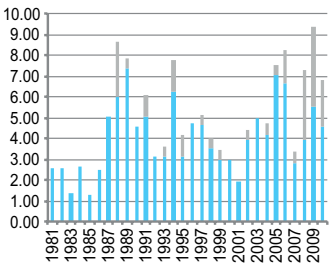
Epispadias



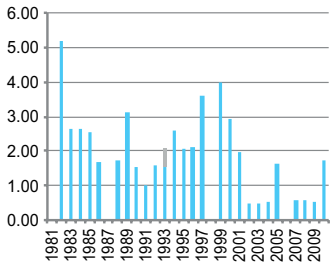
Renal agenesis



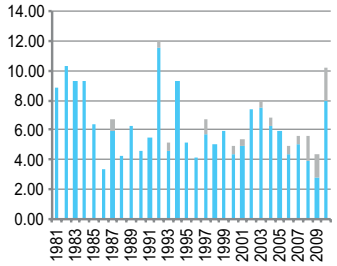
Cystic kidney



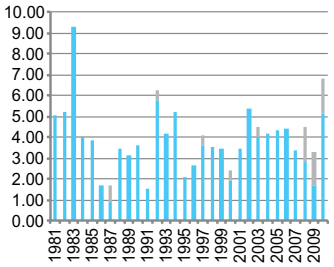
Polydactyly, preaxial



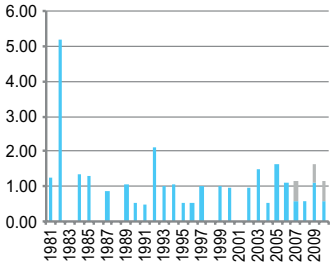
Limb reduction defects



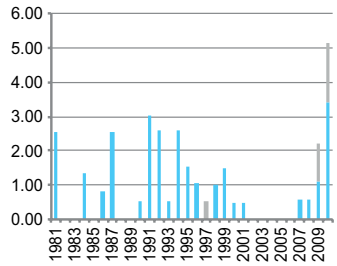
Limb reduction defects - transverse



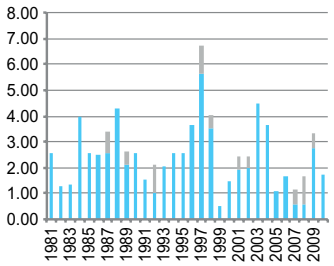
Limb reduction defects - preaxial



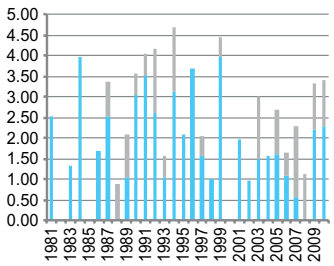
Limb reduction defects - postaxial



Diaphragmatic hernia

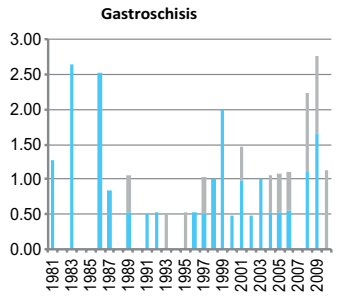


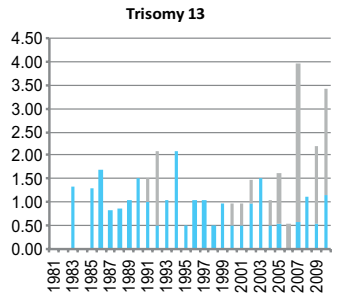
Omphalocele

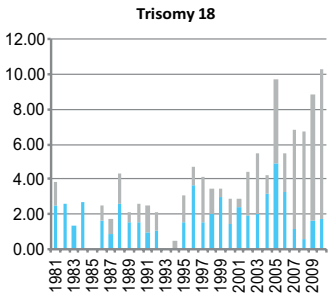


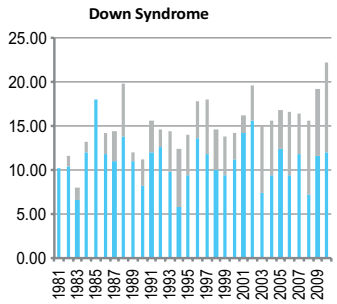
Note: L+S rates, ToP rates

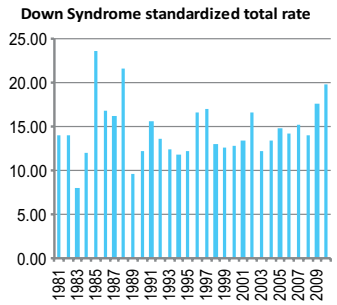
Northern Netherlands











Note: L+S rates, ToP rates

Norway: MBRN
Medical Birth Registry of Norway

History:
The Programme was started in 1967. The Programme was a founding member of the ICBDSR and is a full member.

Size and coverage:
The programme covers all births in Norway, approximately 60,000 annual births.
Notification to MBRN is compulsory for births and pregnancy terminations after 12 weeks of gestation.

Reporting to Clearinghouse includes:
- All live births
- Stillbirths from 20 weeks of gestation or birthweight 300 grams
- Pregnancy terminations from 12 weeks of gestation.

Legislation and funding:
The Programme is run and funded by the governmental Norwegian Institute of Public Health. Reporting is compulsory

Sources of ascertainment:
The registry is based on the notification of births from the delivery units and since 1999 also from the neonatal units.

Exposure information:
Some basic information, such as maternal disease and since 1999, smoking and occupation, is collected on all infants, malformed or not.

Background information:
All information available for the reported malformed infants is also available for the total population of births.

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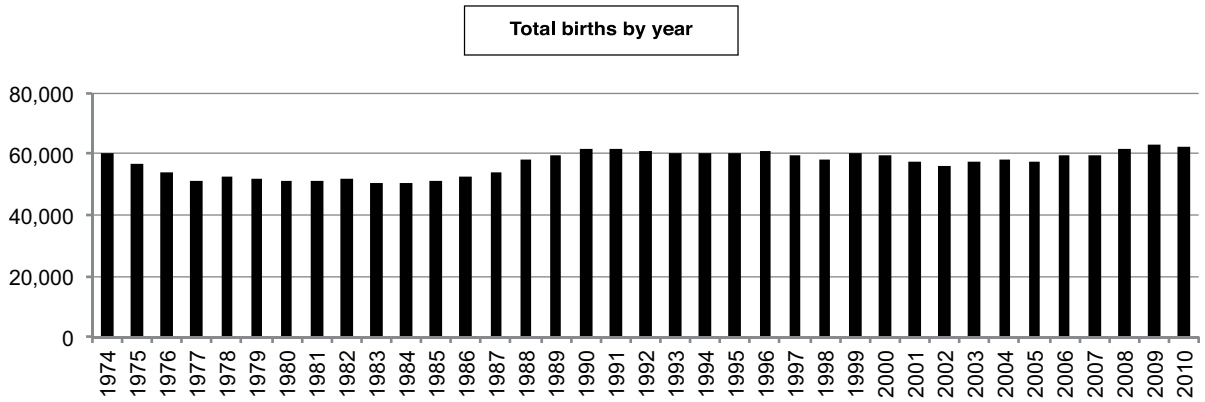
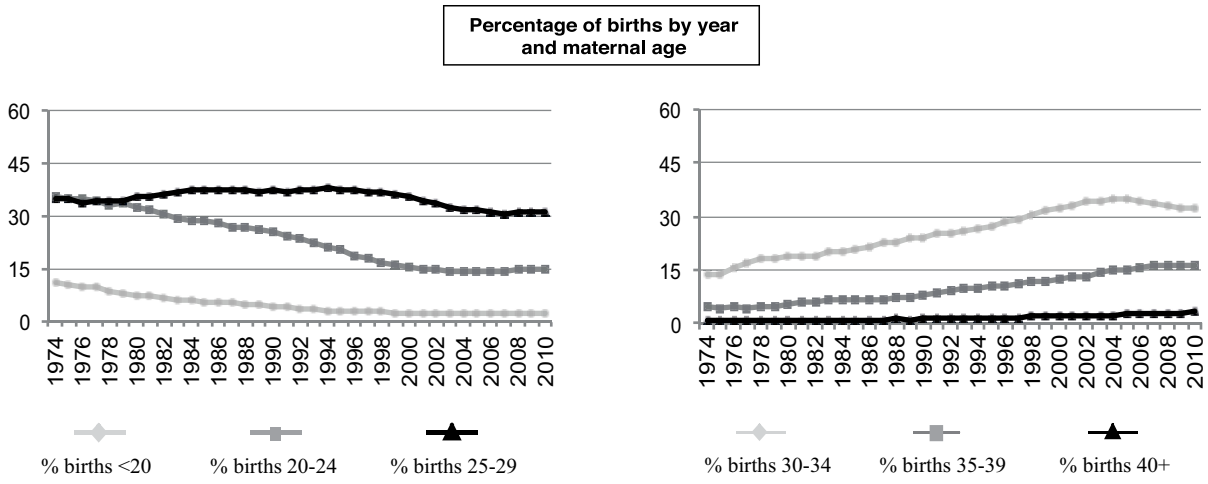
Norway: MBRN





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	58	89.2	Cystic kidney	49	49.0
Spina bifida	58	63.0	Limb reduction defects	33	37.1
Encephalocele	15	88.2	Diaphragmatic hernia	12	21.4
Holoprosencephaly	23	85.2	Omphalocele	34	58.6
Hydrocephaly	39	39.8	Gastroschisis	8	13.1
Hypoplastic left heart syndrome	34	50.7	Trisomy 13	34	79.1
Cleft palate without cleft lip	8	6.3	Trisomy 18	58	69.0
Cleft lip with or without cleft palate	28	12.3	Down syndrome	126	41.2
Renal agenesis	22	75.9			

Total ToPs with births defects = 792 (Ratio ToPs/Births: 4.22 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Norway: MBRN, 2010

Live births (LB)	62,384
Stillbirths (SB)	256
Total births	62,640
Number of terminations of pregnancy (ToP) for birth defects	277

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	2	15	2.71
Spina bifida	12	0	15	4.31
Encephalocele	0	0	3	0.48
Microcephaly	3	0	2	0.80
Holoprosencephaly	0	1	5	0.96
Hydrocephaly	30	0	17	7.50
Anophthalmos	2	1	1	0.64
Microphthalmos	3	0	0	0.48
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	1	0	0.64
Microtia	1	0	0	0.16
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	27	0	3	4.79
Tetralogy of Fallot	14	0	3	2.71
Hypoplastic left heart syndrome	9	0	10	3.03
Coarctation of aorta	31	0	3	5.43
Choanal atresia, bilateral	1	0	1	0.32
Cleft palate without cleft lip	44	0	4	7.66
Cleft lip with or without cleft palate	63	0	9	11.49
Oesophageal atresia/stenosis with or without fistula	20	2	3	3.99
Small intestine atresia/stenosis	4	0	2	0.96
Anorectal atresia/stenosis	25	1	14	6.39
Undescended testis (36 weeks of gestation or later)	120	0	0	19.16
Hypospadias	94	0	0	15.01
Epispadias	2	0	0	0.32
Indeterminate sex	5	0	2	1.12
Renal agenesis	2	2	8	1.92
Cystic kidney	20	0	19	6.23
Bladder exstrophy	2	0	1	0.48
Polydactyly, preaxial	53	1	6	9.58
Total Limb reduction defects (include unspecified)	21	1	14	5.75
Transverse	9	1	3	2.08
Preaxial	5	0	4	1.44
Postaxial	0	0	3	0.48
Intercalary	0	0	0	0.00
Mixed	8	1	6	2.39
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	15	1	3	3.03
Omphalocele	7	1	9	2.71
Gastroschisis	17	1	1	3.03
Unspecified Omphalocele/Gastroschisis	0	2	8	1.60
Prune belly sequence	9	2	14	3.99
Trisomy 13	3	1	10	2.23
Trisomy 18	7	1	20	4.47
Down syndrome, all ages (include age unknown)	69	2	43	18.20
<20	1	0	1	14.57
20-24	8	0	0	8.57
25-29	7	2	0	4.65
30-34	17	0	3	9.85
35-39	26	0	20	44.97
40-44	10	0	18	143.30
45+	0	0	1	99.01
unknown	0	0	0	---

nr = not reported

Norway: MBRN, Previous years rates 1974 - 2010

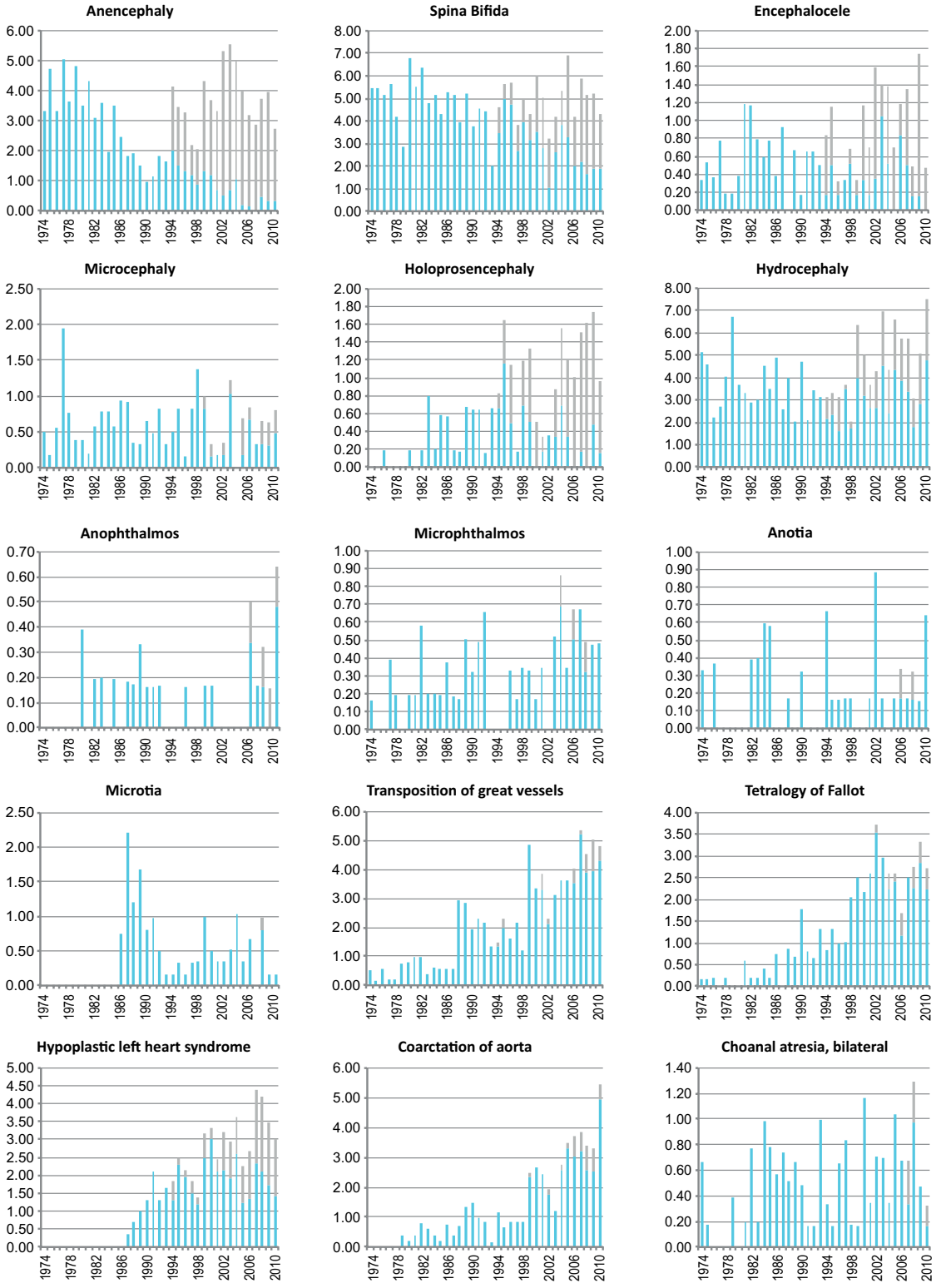
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**378,981**	**255,083**	**286,635**	**303,414**	**299,552**	**287,155**	**306,811**
Anencephaly	4.04	3.29	1.71	2.44	3.10	4.63	3.29
Spina bifida	5.09	5.21	4.64	4.25	4.97	4.95	4.95
Encephalocele	0.40	0.90	0.42	0.76	0.57	1.15	1.04
Microcephaly	0.66	0.59	0.63	0.59	0.73	0.49	0.65
Holoprosencephaly	0.05	0.35	0.45	0.79	0.87	0.87	1.37
Hydrocephaly	4.17	3.45	3.63	3.03	4.04	5.15	5.41
Anophthalmos	0.05	0.12	0.17	0.07	0.10	0.00	0.36
Microphthalmos	0.13	0.27	0.31	0.23	0.27	0.42	0.55
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.11	0.39	0.10	0.16	0.10	0.28	0.33
Microtia	nr	nr	1.33	0.43	0.47	0.52	0.39
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.45	0.71	1.81	1.91	2.64	3.31	4.76
Tetralogy of Fallot	0.11	0.31	0.84	0.99	1.74	2.89	2.61
Hypoplastic left heart syndrome	nr	nr	0.86*	1.88	2.37	2.89	3.55
Coarctation of aorta	0.29*	0.47	0.94	0.76	1.54	2.37	3.94
Choanal atresia, bilateral	0.18	0.59	0.59	0.36	0.60	0.63	0.68
Cleft palate without cleft lip	4.75	5.21	5.62	5.17	6.04	6.62	7.04
Cleft lip with or without cleft palate	14.41	13.56	14.13	13.32	13.22	12.82	12.94
Oesophageal atresia/stenosis with or without fistula	1.98	1.80	2.37	2.04	2.20	2.61	3.16
Small intestine atresia/stenosis	0.95	1.02	1.26	1.55	1.37	0.94	0.91
Anorectal atresia/stenosis	1.61	2.20	2.13	2.31	2.47	2.68	4.33
Undescended testis (36 weeks of gestation or later)	17.81	14.07	16.29	17.20	18.19	28.38	23.43
Hypospadias	13.09	14.00	16.33	15.39	14.59	16.44	13.43
Epispadias	0.26	0.47	0.38	0.16	0.37	0.14	0.20
Indeterminate sex	2.51	4.08	3.98	7.05	4.84	0.38	0.59
Renal agenesis	0.13	1.06	1.29	1.52	1.50	0.91	1.83
Cystic kidney	0.47	1.18	1.60	2.47	3.54	4.95	5.57
Bladder exstrophy	0.24	0.55	0.24	0.26	0.37	0.28	0.36
Polydactyly, preaxial	nr	nr	nr	nr	8.09*	8.98	8.80
Total Limb reduction defects (include unspecified)	8.39	6.82	7.19	6.86	5.68	4.07	4.92
Transverse	nr	nr	2.97*	4.05	2.27	2.37	2.09
Preaxial	nr	nr	0.83*	0.56	0.50	0.42	0.91
Postaxial	nr	nr	0.83*	0.49	0.33	0.07	0.26
Intercalary	nr	nr	0.25*	0.36	0.43	0.10	0.10
Mixed	nr	nr	0.41*	0.66	1.34	1.43	2.18
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	2.01	2.55	2.34	2.47	2.74	2.58	2.90
Omphalocele	2.32	1.88	2.13	1.98	2.24	2.37	2.84
Gastroschisis	1.32	1.49	1.92	2.24	2.84	2.72	3.32
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	1.08*	0.35	0.78
Prune belly sequence	nr	nr	nr	nr	1.33*	1.29	2.64
Trisomy 13	nr	nr	nr	nr	1.83*	1.18	2.38
Trisomy 18	nr	nr	nr	nr	2.92*	3.83	4.69
Down syndrome, all ages (include age unknown)	9.79	10.55	10.92	10.28	13.42	17.90	17.70
<20	2.25	5.45	3.47	2.79	2.46	7.68	5.58
20-24	6.27	7.11	6.58	5.64	2.75	6.29	6.72
25-29	7.80	6.83	6.01	7.18	6.85	7.44	7.49
30-34	10.78	14.15	13.36	11.15	11.13	13.66	12.35
35-39	37.22	33.97	37.42	20.98	38.99	43.65	45.74
40-44	127.11	63.72	80.22	84.51	130.85	151.95	136.67
45+	197.04	93.46	267.86	342.47	253.16	241.94	227.27
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

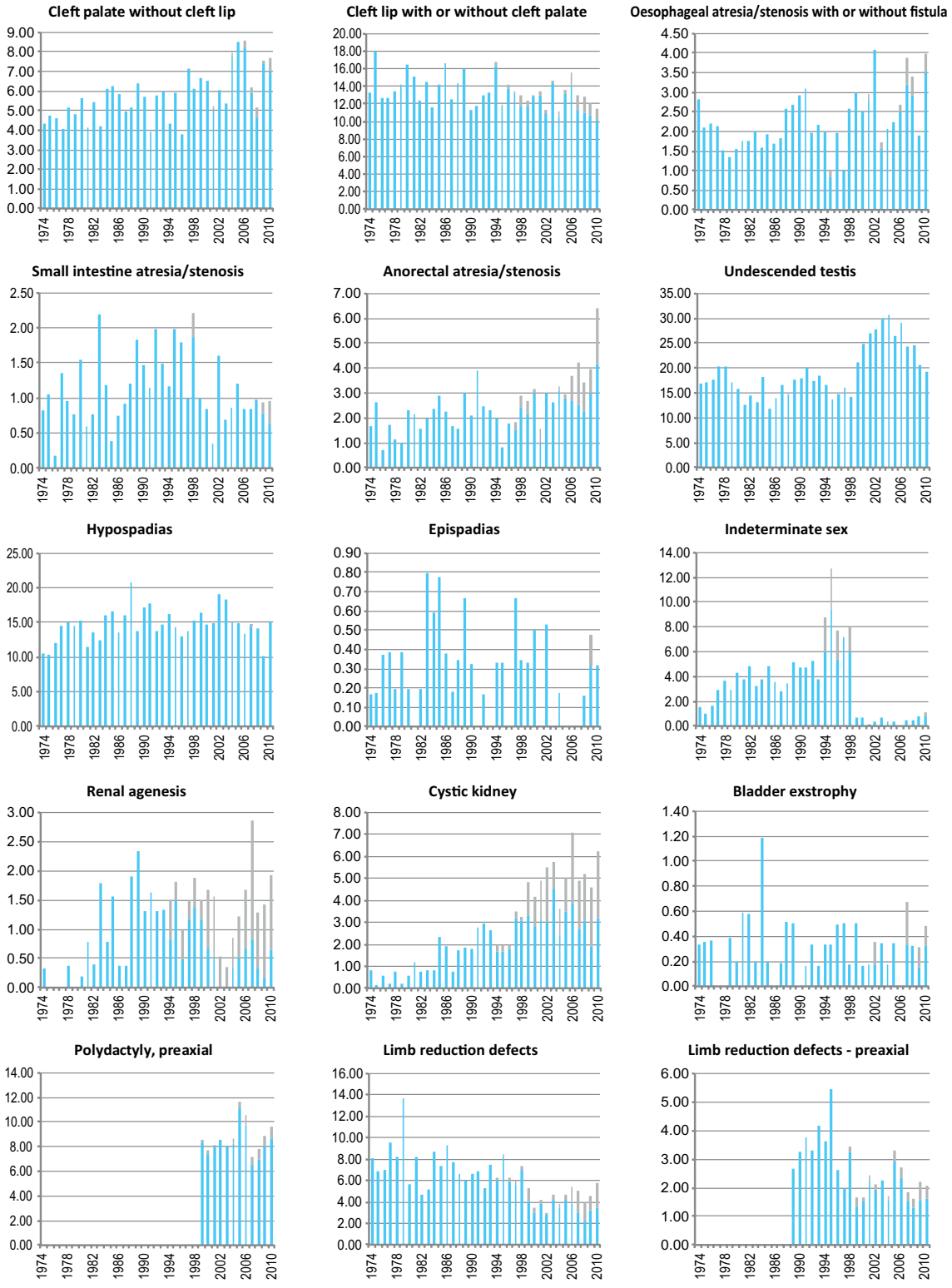
Norway: MBRN

Time trends 1974-2010 (Birth prevalence rates per 10,000)



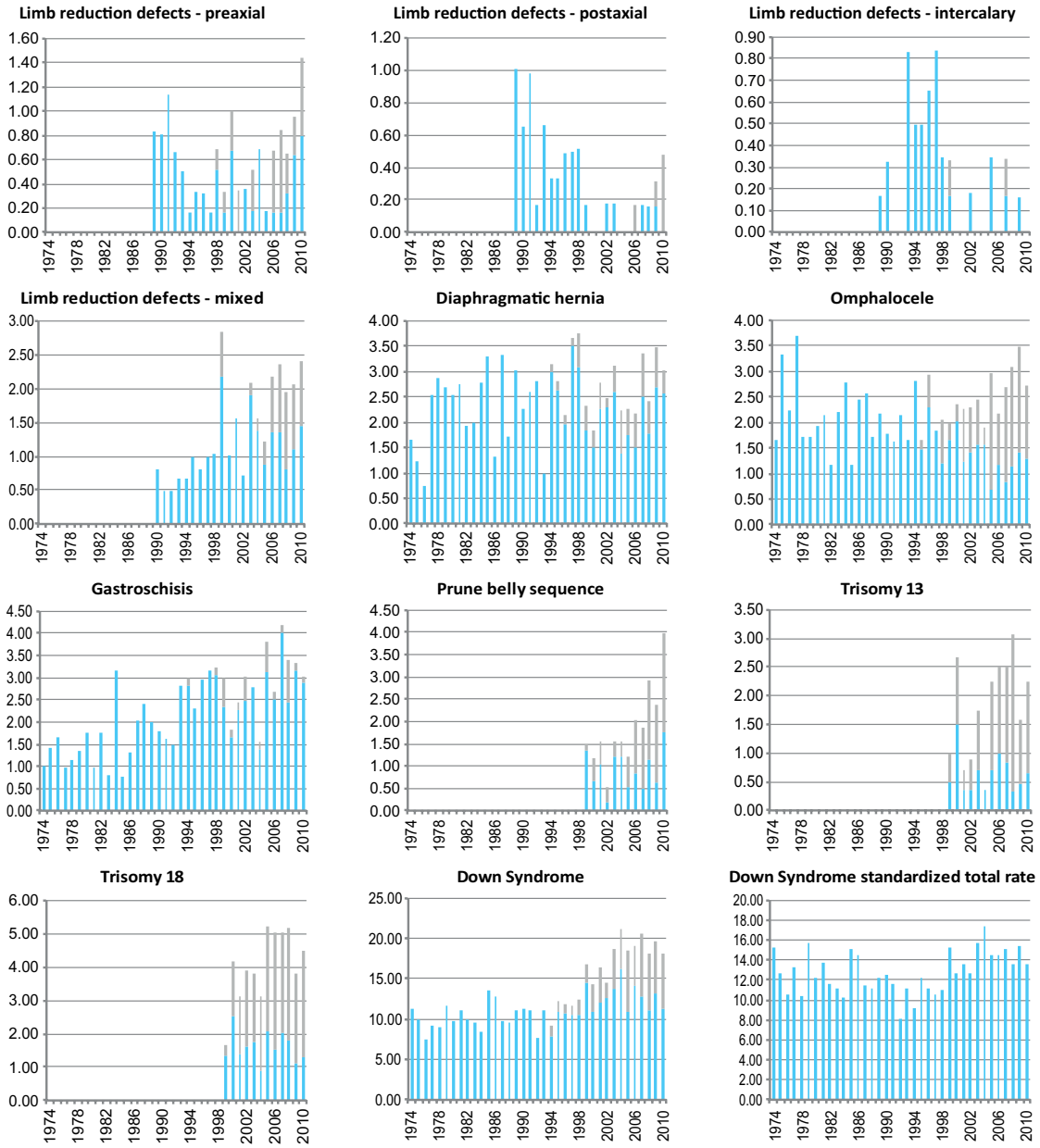
Note: L+S rates, ToP rates

Norway: MBRN



Note: L+S rates, ToP rates

Norway: MBRN



Note: L+S rates, ToP rates

Saudi Arabia: MSD-BDR

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Saudi Arabia, 2010 (January-June)

Live births (LB)	4,970
Stillbirths (SB)	7
Total births	4,977
Number of terminations of pregnancy (ToP) for birth defects	3

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	1	1	10.05
Spina bifida	1	0	0	2.01
Encephalocele	1	0	0	2.01
Microcephaly	6	0	0	12.06
Holoprosencephaly	1	0	0	2.01
Hydrocephaly	5	1	0	12.06
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	0	4.02
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	3	0	0	6.03
Tetralogy of Fallot	3	0	0	6.03
Hypoplastic left heart syndrome	2	0	0	4.02
Coarctation of aorta	1	0	0	2.01
Choanal atresia, bilateral	1	0	0	2.01
Cleft palate without cleft lip	1	0	0	2.01
Cleft lip with or without cleft palate	6	1	0	14.06
Oesophageal atresia/stenosis with or without fistula	4	0	0	8.04
Small intestine atresia/stenosis	2	0	0	4.02
Anorectal atresia/stenosis	2	0	0	4.02
Undescended testis (36 weeks of gestation or later)	0	0	0	0.00
Hypospadias	7	0	0	14.06
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	6	1	1	16.07
Cystic kidney	6	0	0	12.06
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	5	0	0	10.05
Total Limb reduction defects (include unspecified)	2	0	0	4.02
Transverse	1	0	0	2.01
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	1	0	0	2.01
Mixed	0	0	0	0.00
Unspecified	0	0	0	0.00
Diaphragmatic hernia	2	0	0	4.02
Omphalocele	1	0	0	2.01
Gastroschisis	0	0	0	0.00
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	2.01
Trisomy 13	0	0	0	0.00
Trisomy 18	3	1	0	8.04
Down syndrome, all ages (include age unknown)	12	1	0	26.12
<20	0	0	0	0.00
20-24	1	0	0	9.26
25-29	2	0	0	13.44
30-34	1	0	0	8.05
35-39	4	0	0	54.57
40-44	4	0	0	170.21
45+	0	1	0	256.41
unknown	0	0	0	---

Slovak Republic

Slovak Teratologic Information Centre, Slovak Medical University

History:
All „Reports on Birth Defects" from neonatal clinics in Slovakia receives and processes the National Health Information Centre of SR (NHIC). The obligation to report all categories of congenital malformations results from valid legislative standards. Reporting of congenital malformations began in 1964.The Programme of Slovak Teratological Information Center (STIC) was established in 2003 year and consists in cooperation of the Slovak Medical University, NHIC and the Centers of Medical Genetics or neonatal clinics. Work on research projects with the issue of congenital malformation and collaboration with Departmens of Clinical Genetics in Slovakia started from 1995 year, under the responsibility of Dr. Elena Szabova, PhD.

Size and coverage:
The registry covers all births in about 55. 000- 60. 000 births per year, received from NHIC, by the Reports of birth defects". The detailed information about cases of CM are collected in the Centers of Medical Genetics, or under the running research projects at the Slovak Medical University.

Legislation and funding:
Reporting is compulsory. Analysis of data is supported by grant projects.

Sources of ascertainment:
Reports are received from NHIC, delivery units, neonatal, pediatric clinics, or departments of clinical genetics.

Exposure Information:
Detailed information on maternal and paternal occupation, drug use, etc. are collected by interviews of case´s and control´s mothers only according to running research projects.

Background information:
Some background information is available from the general population statistics.

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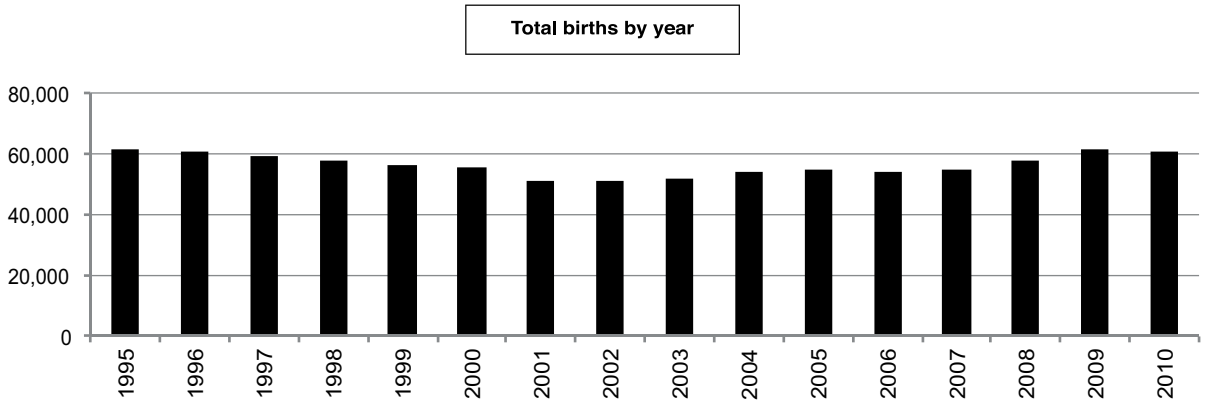
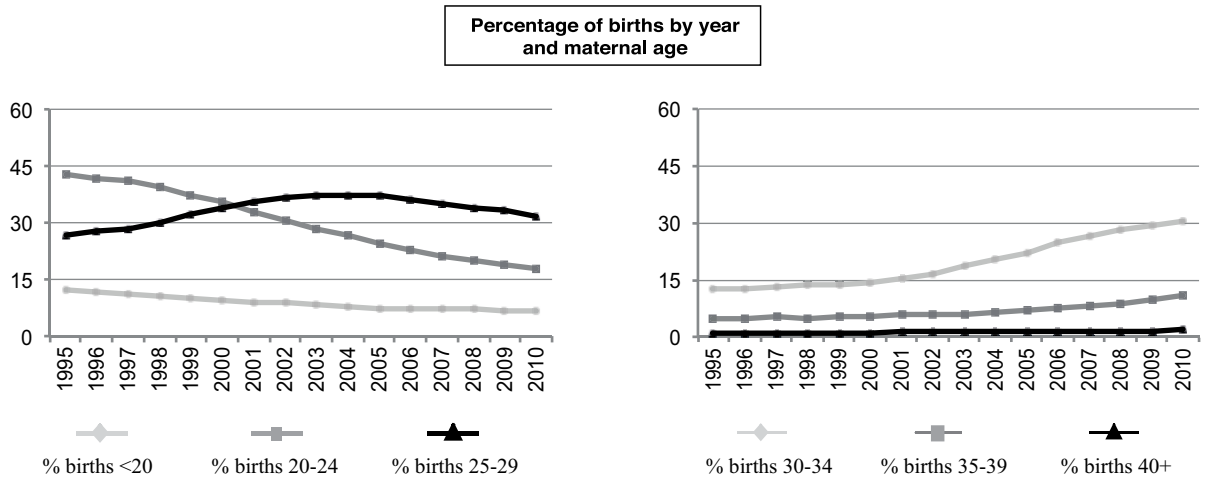
Slovak Republic





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	12	66.7	Cystic kidney	1	6.3
Spina bifida	3	7.7	Limb reduction defects	0	0.0
Encephalocele	5	41.7	Diaphragmatic hernia	1	2.9
Holoprosencephaly	1	16.7	Omphalocele	3	37.5
Hydrocephaly	13	27.1	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	1	33.3
Cleft palate without cleft lip	2	2.5	Trisomy 18	6	31.6
Cleft lip with or without cleft palate	1	0.6	Down syndrome	46	27.7
Renal agenesis	2	1.9			

Total ToPs with births defects = 166 (Ratio ToPs/Births: 0.92 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Slovak Republic, 2010

Live births (LB)	60,410
Stillbirths (SB)	189
Total births	60,599
Number of terminations of pregnancy (ToP) for birth defects	66

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	2	8	1.65
Spina bifida	10	1	0	1.82
Encephalocele	3	0	3	0.99
Microcephaly	5	0	0	0.83
Holoprosencephaly	3	0	1	0.66
Hydrocephaly	13	0	6	3.14
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.17
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.17
Microtia	2	0	0	0.33
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	16	0	0	2.64
Tetralogy of Fallot	8	0	1	1.49
Hypoplastic left heart syndrome	10	0	0	1.65
Coarctation of aorta	5	0	0	0.83
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	24	0	2	4.29
Cleft lip with or without cleft palate	60	0	1	10.07
Oesophageal atresia/stenosis with or without fistula	5	0	0	0.83
Small intestine atresia/stenosis	6	0	0	0.99
Anorectal atresia/stenosis	19	0	0	3.14
Undescended testis (36 weeks of gestation or later)	87	0	0	14.36
Hypospadias	95	0	0	15.68
Epispadias	3	0	0	0.50
Indeterminate sex	2	0	0	0.33
Renal agenesis	41	0	1	6.93
Cystic kidney	5	0	1	0.99
Bladder exstrophy	2	0	0	0.33
Polydactyly, preaxial	22	0	0	3.63
Total Limb reduction defects (include unspecified)	21	0	0	3.47
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	11	0	0	1.82
Omphalocele	0	0	2	0.33
Gastroschisis	7	0	0	1.16
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	1	0	0.17
Trisomy 18	5	0	4	1.49
Down syndrome, all ages (include age unknown)	37	0	14	8.42
<20	1	0	0	2.45
20-24	1	0	1	1.84
25-29	2	0	2	2.07
30-34	13	0	5	9.75
35-39	10	0	4	20.66
40-44	8	0	2	96.71
45+	2	0	0	392.16
unknown	0	0	0	---

nr = not reported

Slovak Republic, Previous years rates 1995 - 2010

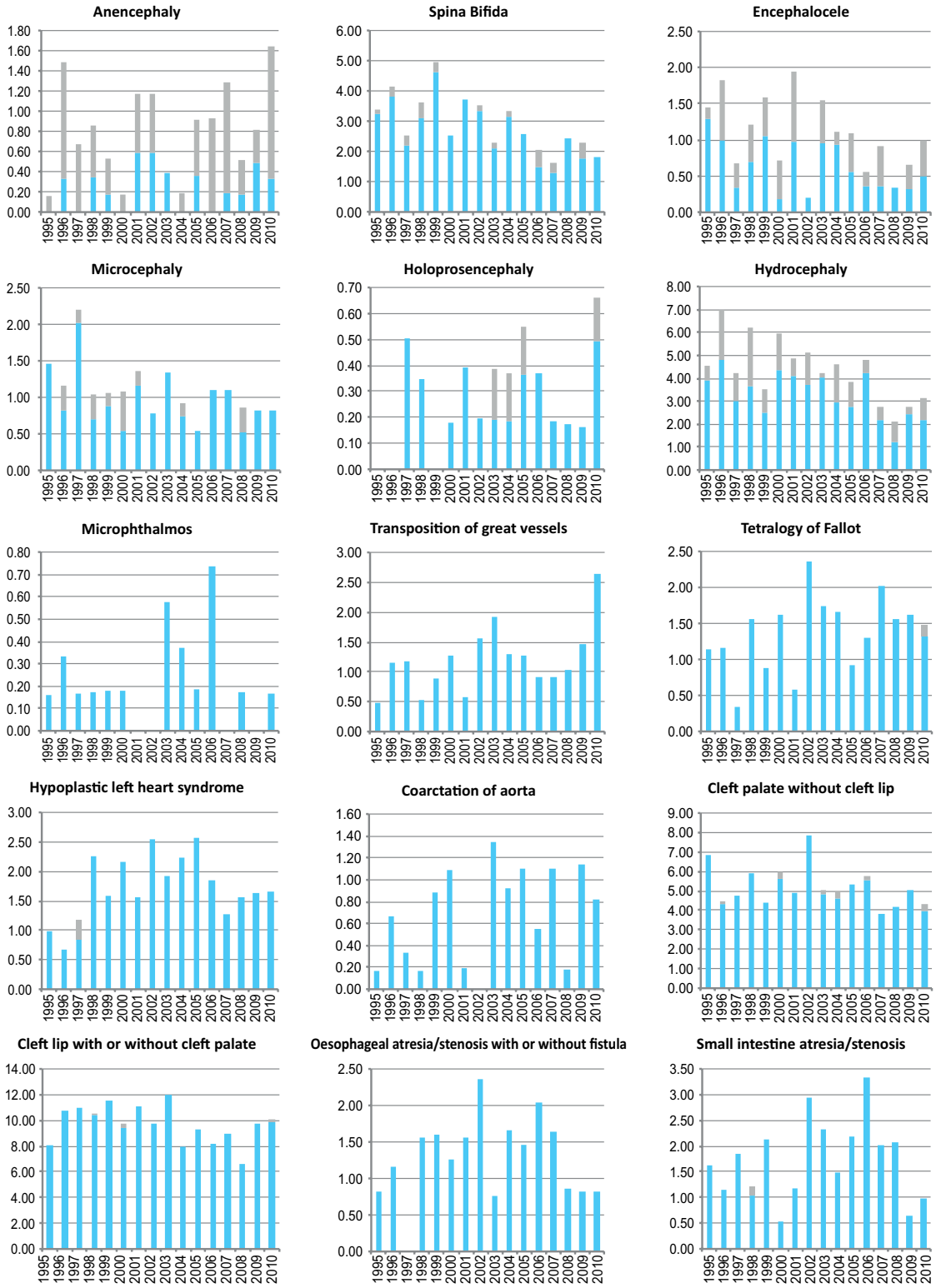
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995*	1996-2000	2001-2005	2006-2010
Total births				**61,668**	**289,430**	**262,891**	**288,383**
Anencephaly				0.16	0.76	0.76	1.04
Spina bifida				3.41	3.56	3.08	2.05
Encephalocele				1.46	1.21	1.18	0.69
Microcephaly				1.46	1.31	0.99	0.94
Holoprosencephaly				0.00	0.21	0.38	0.31
Hydrocephaly				4.54	5.39	4.53	3.09
Anophthalmos				0.00	0.07	0.04	0.03
Microphthalmos				0.16	0.21	0.23	0.21
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.00	0.00
Anotia				0.00	0.17	0.08	0.17
Microtia				0.00	0.41	0.27	0.14
Unspecified Anotia/Microtia				0.16	0.17	0.61	0.92*
Transposition of great vessels				0.49	1.00	1.33	1.42
Tetralogy of Fallot				1.14	1.11	1.45	1.60
Hypoplastic left heart syndrome				0.97	1.55	2.17	1.60
Coarctation of aorta				0.16	0.62	0.72	0.76
Choanal atresia, bilateral				0.16	0.24	0.15	0.17
Cleft palate without cleft lip				6.81	5.08	5.59	4.61
Cleft lip with or without cleft palate				8.11	10.71	10.00	8.74
Oesophageal atresia/stenosis with or without fistula				0.81	1.11	1.56	1.21
Small intestine atresia/stenosis				1.62	1.38	2.02	1.77
Anorectal atresia/stenosis				0.65	1.76	3.16	2.77
Undescended testis (36 weeks of gestation or later)				3.73	7.19	8.06	11.37
Hypospadias				25.30	22.56	23.43	16.92
Epispadias				0.16	0.17	0.15	0.24
Indeterminate sex				0.00	0.59	0.30	0.24
Renal agenesis				1.14	3.18	5.90	5.96
Cystic kidney				0.16	1.04	1.60	1.11
Bladder exstrophy				0.00	0.21	0.15	0.07
Polydactyly, preaxial				1.30	1.80	3.65	2.64
Total Limb reduction defects (include unspecified)				3.41	3.63	3.88	2.91
Transverse				nr	nr	nr	nr
Preaxial				nr	nr	nr	nr
Postaxial				nr	nr	nr	nr
Intercalary				nr	nr	nr	nr
Mixed				nr	nr	nr	nr
Unspecified				0.16	0.00	0.04	0.00*
Diaphragmatic hernia				0.81	1.38	1.52	1.87
Omphalocele				0.49	0.52	0.80	0.45
Gastroschisis				0.32	1.07	0.91	1.01
Unspecified Omphalocele/Gastroschisis				0.00	0.00	0.00	0.17*
Prune belly sequence				0.00	0.03	0.23	0.03
Trisomy 13				0.16	0.24	0.42	0.24
Trisomy 18				0.16	0.31	0.57	0.73
Down syndrome, all ages (include age unknown)				7.95	9.57	10.46	8.63
<20				7.91	6.53	3.64	2.46*
20-24				6.09	6.44	3.85	3.01*
25-29				3.03	6.81	7.02	4.91*
30-34				16.68	11.70	11.83	9.56*
35-39				27.93	34.02	45.98	23.17*
40-44				16.69	81.58	106.02	87.27*
45+				0.00	243.90	230.77	228.57*
unknown				---	---	---	---

nr = not reported
* data include less than 5 years

Slovak Republic

Time trends 1995-2010 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

Slovak Republic

Note: L+S rates, ToP rates

South America: ECLAMC

Latin American Collaborative Study of Congenital Malformations

History:
The Programme started in 1967 and has grown in size and coverage. The Programme became a full member of the International Clearinghouse in 1977.

Size and coverage:
The number of participating hospitals has grown from 20 in 1977 to 70 at the present time, distributed over most South Americans countries. The annual number of births covered is at present approximately 150,000, less than 1% of all births. Stillbirths of at least 500g birthweight have been included since 1978.

Legislation and funding:
The Programme is a research Programme with voluntary participation of hospitals and funded by research grants provided from several sources, mainly the national research councils of Argentina and Brazil.

Sources of ascertainment:
Reporting is made by collaborating pediatricians at the delivery units of participating hospitals.

Exposure information:
The mother of each reported infant and the mother of a control infant - the next non-malformed infant born at that hospital with the same sex as the proband - are interviewed on various exposures, including drug usage and parental occupation.

Background information:
Background information is obtained partly from summarising tables of births in each participating hospitals, partly from the matched control newborns.

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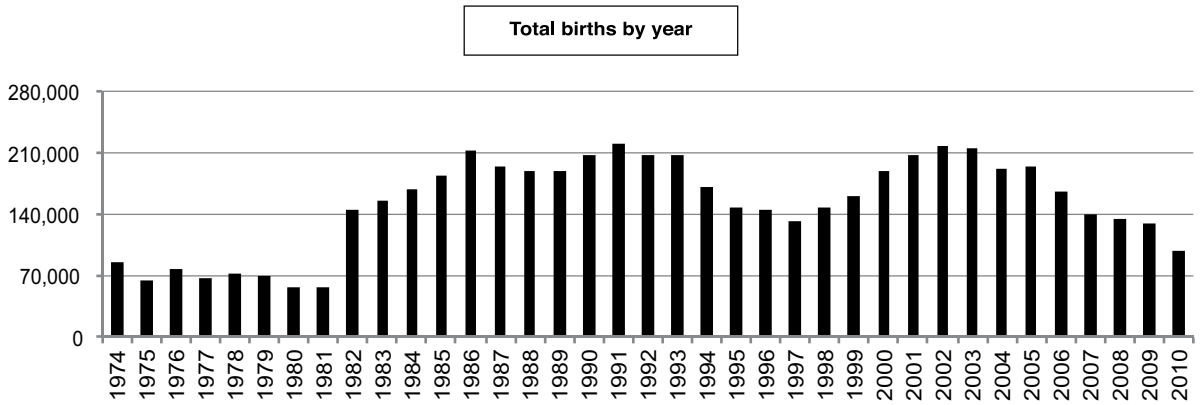
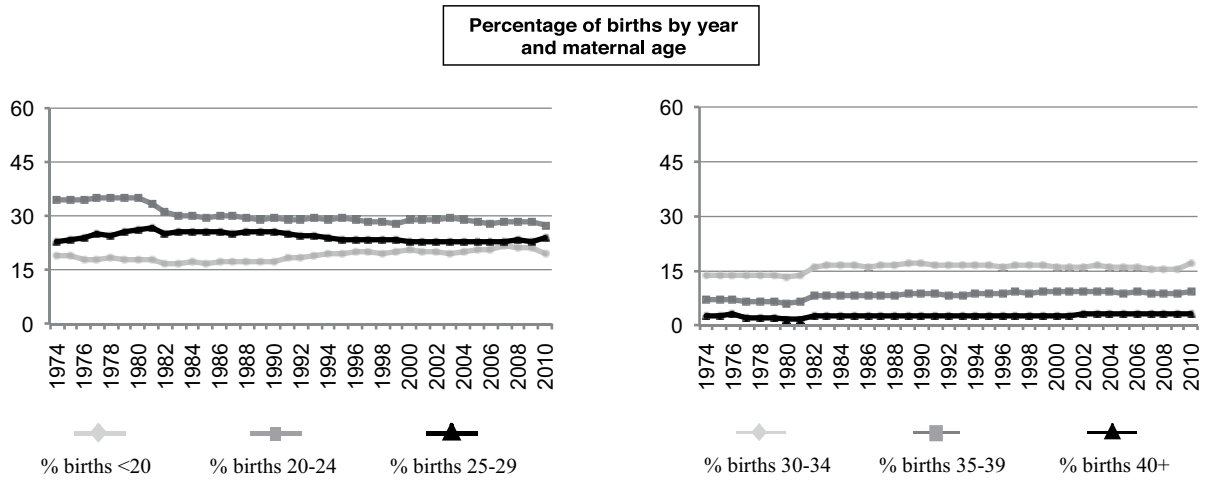
South America: ECLAMC





South America: ECLAMC, 2010

Live births (LB)	96,493
Stillbirths (SB)	1,188
Total births	97,681
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	37	27		6.55
Spina bifida	81	3		8.60
Encephalocele	26	9		3.58
Microcephaly	58	7		6.65
Holoprosencephaly	7	1		0.82
Hydrocephaly	194	16		21.50
Anophthalmos	9	2		1.13
Microphthalmos	14	0		1.43
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	1	2		0.31
Microtia	66	5		7.27
Unspecified Anotia/Microtia	6	1		0.72
Transposition of great vessels	5	0		0.51
Tetralogy of Fallot	16	1		1.74
Hypoplastic left heart syndrome	10	1		1.13
Coarctation of aorta	2	1		0.31
Choanal atresia, bilateral	2	1		0.31
Cleft palate without cleft lip	42	7		5.02
Cleft lip with or without cleft palate	110	12		12.49
Oesophageal atresia/stenosis with or without fistula	46	3		5.02
Small intestine atresia/stenosis	22	2		2.46
Anorectal atresia/stenosis	54	9		6.45
Undescended testis (36 weeks of gestation or later)	95	2		9.93
Hypospadias	94	5		10.14
Epispadias	2	0		0.20
Indeterminate sex	30	7		3.79
Renal agenesis	34	7		4.20
Cystic kidney	57	7		6.55
Bladder exstrophy	3	0		0.31
Polydactyly, preaxial	29	2		3.17
Total Limb reduction defects (include unspecified)	68	8		7.78
Transverse	7	0		0.72
Preaxial	9	3		1.23
Postaxial	1	0		0.10
Intercalary	1	2		0.31
Mixed	2	0		0.20
Unspecified	48	3		5.22
Diaphragmatic hernia	33	3		3.69
Omphalocele	47	5		5.32
Gastroschisis	102	5		10.95
Unspecified Omphalocele/Gastroschisis	10	4		1.43
Prune belly sequence	3	0		0.31
Trisomy 13	7	1		0.82
Trisomy 18	12	9		2.15
Down syndrome, all ages (include age unknown)	172	7		18.32
<20	12	0		6.55
20-24	19	0		7.34
25-29	21	4		11.11
30-34	29	0		18.38
35-39	48	2		57.63
40-44	37	1		146.55
45+	5	0		185.87
unknown	1	0		---

South America: ECLAMC, Previous years rates 1974 - 2010

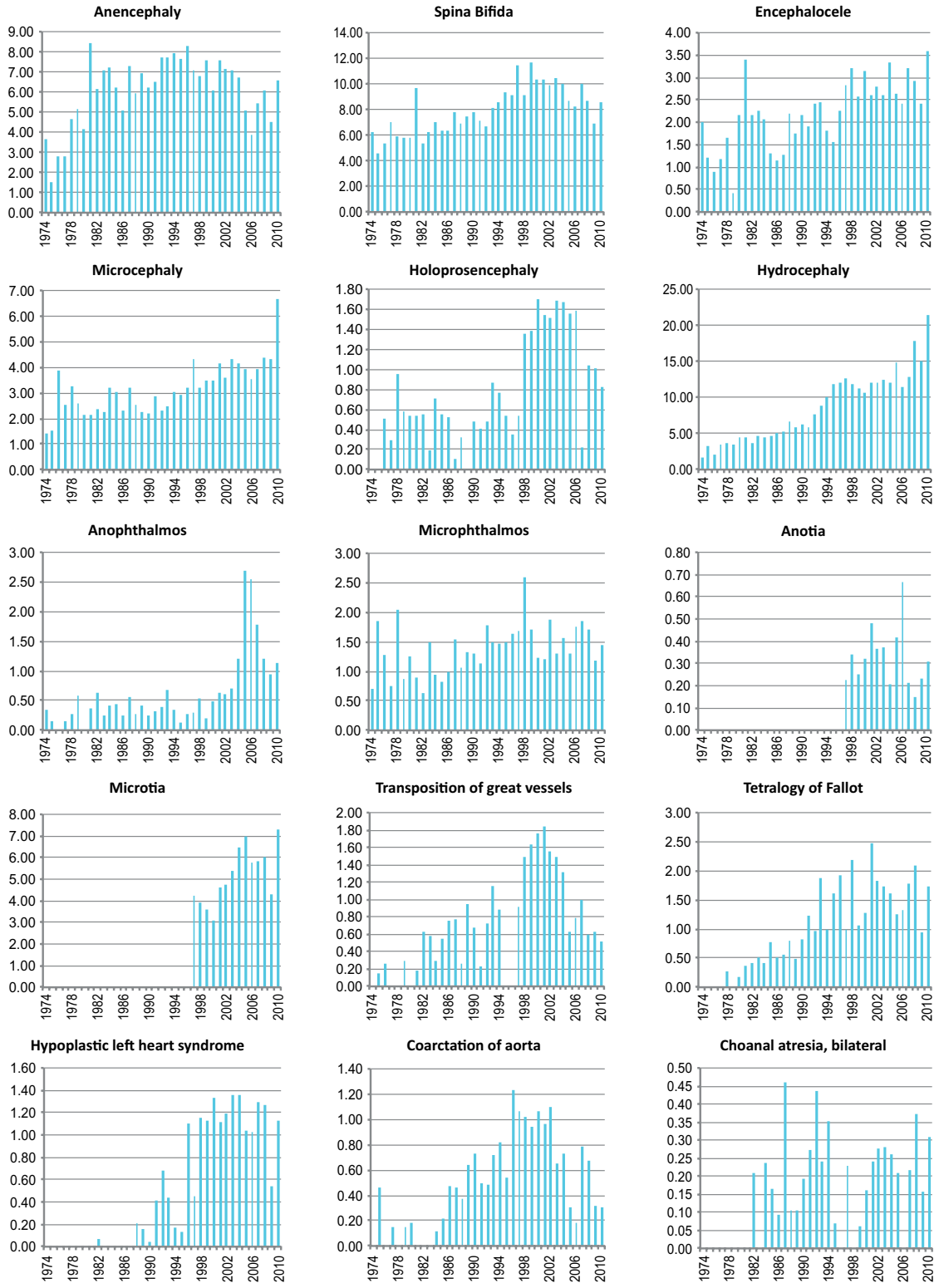
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**493,467**	**706,137**	**992,563**	**953,726**	**771,185**	**1,023,502**	**664,200**
Anencephaly	3.55	6.81	6.28	7.45	7.12	6.74	5.16
Spina bifida	5.82	6.56	7.25	7.86	10.35	9.91	8.51
Encephalocele	1.36	2.04	1.70	2.07	2.81	2.79	2.86
Microcephaly	2.49	2.69	2.50	2.71	3.51	4.03	4.40
Holoprosencephaly	0.41	0.51	0.29	0.61	1.12	1.59	0.96
Hydrocephaly	3.06	4.39	5.80	8.63	11.63	12.62	15.18
Anophthalmos	0.22	0.42	0.34	0.39	0.36	1.13	1.60
Microphthalmos	1.24	0.96	1.24	1.47	1.74	1.46	1.61
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	0.29*	0.37	0.33
Microtia	nr	nr	nr	nr	3.66*	5.60	5.77
Unspecified Anotia/Microtia	nr	nr	nr	nr	0.14*	0.07	0.26
Transposition of great vessels	0.10	0.48	0.69	0.73	1.21	1.38	0.72
Tetralogy of Fallot	0.06	0.52	0.63	1.33	1.48	1.79	1.57
Hypoplastic left heart syndrome	0.00	0.01	0.08	0.39	1.06	1.21	1.05
Coarctation of aorta	0.12	0.08	0.53	0.61	1.06	0.76	0.45
Choanal atresia, bilateral	0.00	0.14	0.19	0.28	0.09	0.25	0.20
Cleft palate without cleft lip	3.14	3.48	3.33	3.92	3.89	5.26	4.02
Cleft lip with or without cleft palate	10.98	10.22	10.72	10.84	12.77	13.94	11.95
Oesophageal atresia/stenosis with or without fistula	1.97	2.51	2.66	2.95	3.50	3.70	3.69
Small intestine atresia/stenosis	0.57	1.67	1.42	1.82	2.41	3.20	2.56
Anorectal atresia/stenosis	2.76	3.84	3.84	4.48	5.15	5.69	5.27
Undescended testis (36 weeks of gestation or later)	1.54	3.94	4.53	4.83	5.55	6.86	10.24
Hypospadias	3.53	4.87	3.79	4.59	5.36	4.63	8.16
Epispadias	0.12	0.41	0.27	0.31	0.18	0.18	0.18
Indeterminate sex	1.07	2.24	1.89	1.80	1.88	2.38	2.74
Renal agenesis	0.43	0.69	1.02	1.67	2.40	2.51	2.76
Cystic kidney	0.57	1.10	1.74	2.09	3.99	4.13	4.64
Bladder exstrophy	0.12	0.28	0.28	0.22	0.39	0.32	0.24
Polydactyly, preaxial	2.76	2.46	2.47	2.75	2.98	4.13	3.45
Total Limb reduction defects (include unspecified)	4.17	5.57	4.76	5.55	6.44	7.18	7.56
Transverse	2.27	2.69	2.56	2.80	3.13	3.62	1.91
Preaxial	0.63	1.13	0.94	1.15	1.66	1.38	1.14
Postaxial	0.26	0.50	0.27	0.44	0.45	0.38	0.45
Intercalary	0.45	0.55	0.35	0.49	0.58	0.53	0.81
Mixed	0.45	0.62	0.50	0.50	0.52	1.09	1.91
Unspecified	0.12	0.07	0.13	0.16	0.10	0.19	1.32
Diaphragmatic hernia	0.81	1.26	1.83	2.40	3.64	3.78	3.48
Omphalocele	1.09	2.20	2.24	2.61	3.18	3.70	4.29
Gastroschisis	0.08	0.47	0.62	1.51	2.88	3.61	8.49
Unspecified Omphalocele/Gastroschisis	0.34	0.47	0.34	0.61	1.19	1.34	0.30
Prune belly sequence	0.02	0.64	0.75	0.81	1.18	0.94	0.69
Trisomy 13	0.18	0.59	0.36	0.57	0.80	0.96	0.53
Trisomy 18	0.24	0.86	0.88	1.20	1.88	1.91	1.39
Down syndrome, all ages (include age unknown)	14.63	15.05	15.04	15.86	18.79	19.46	17.34
<20	7.62	6.36	7.08	6.87	7.98	7.67	8.78
20-24	7.12	6.75	7.27	7.67	9.68	9.29	7.80
25-29	8.14	8.02	7.14	8.45	10.21	9.60	9.28
30-34	13.99	15.12	16.20	15.16	17.44	16.51	16.90
35-39	54.11	43.66	45.57	47.05	52.49	57.19	50.24
40-44	163.64	158.38	134.57	156.76	181.76	176.99	142.97
45+	295.12	248.45	278.51	281.23	315.96	422.94	256.41
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

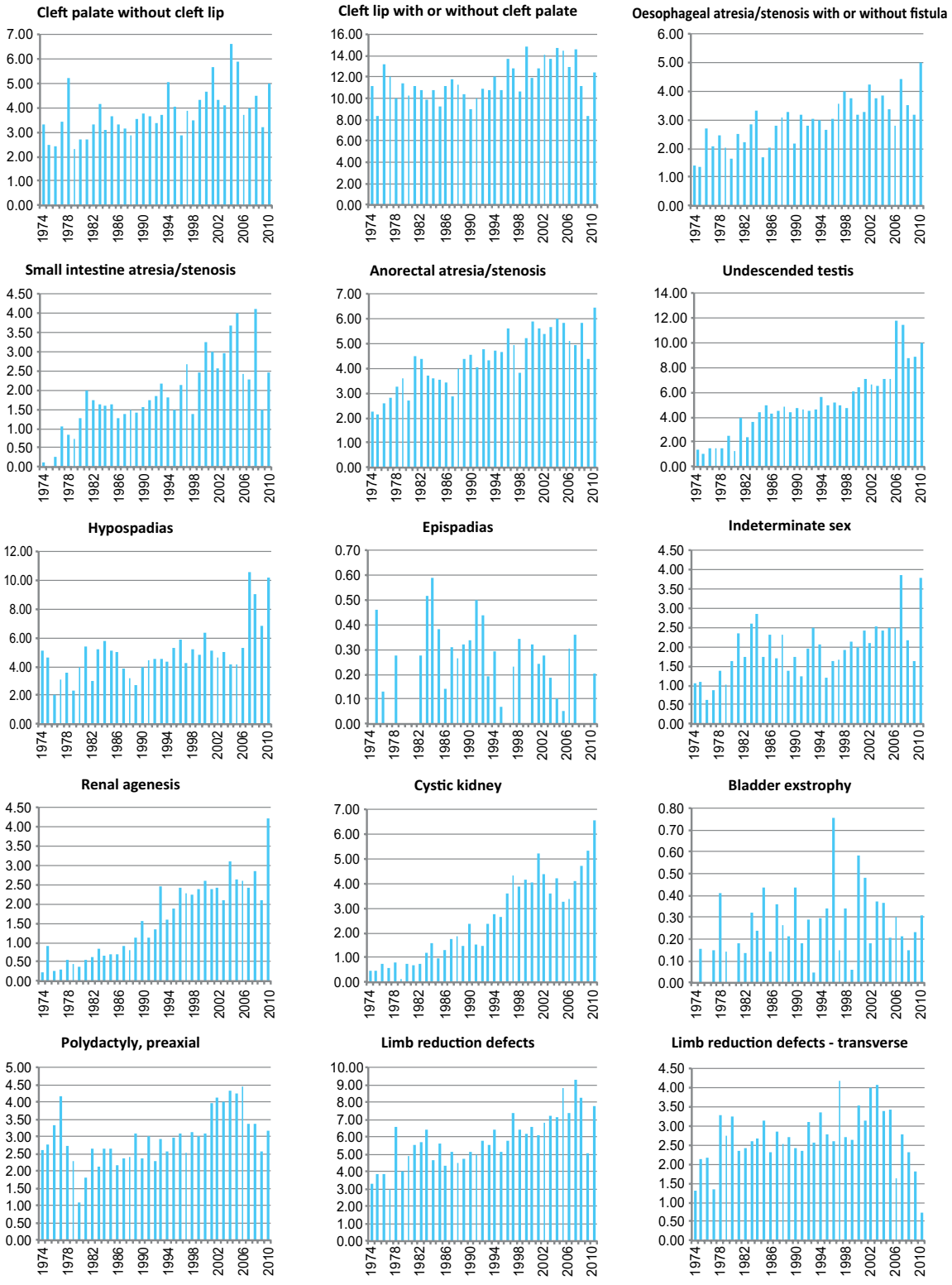
South America: ECLAMC

Time trends 1974-2010 (Birth prevalence rates per 10,000)



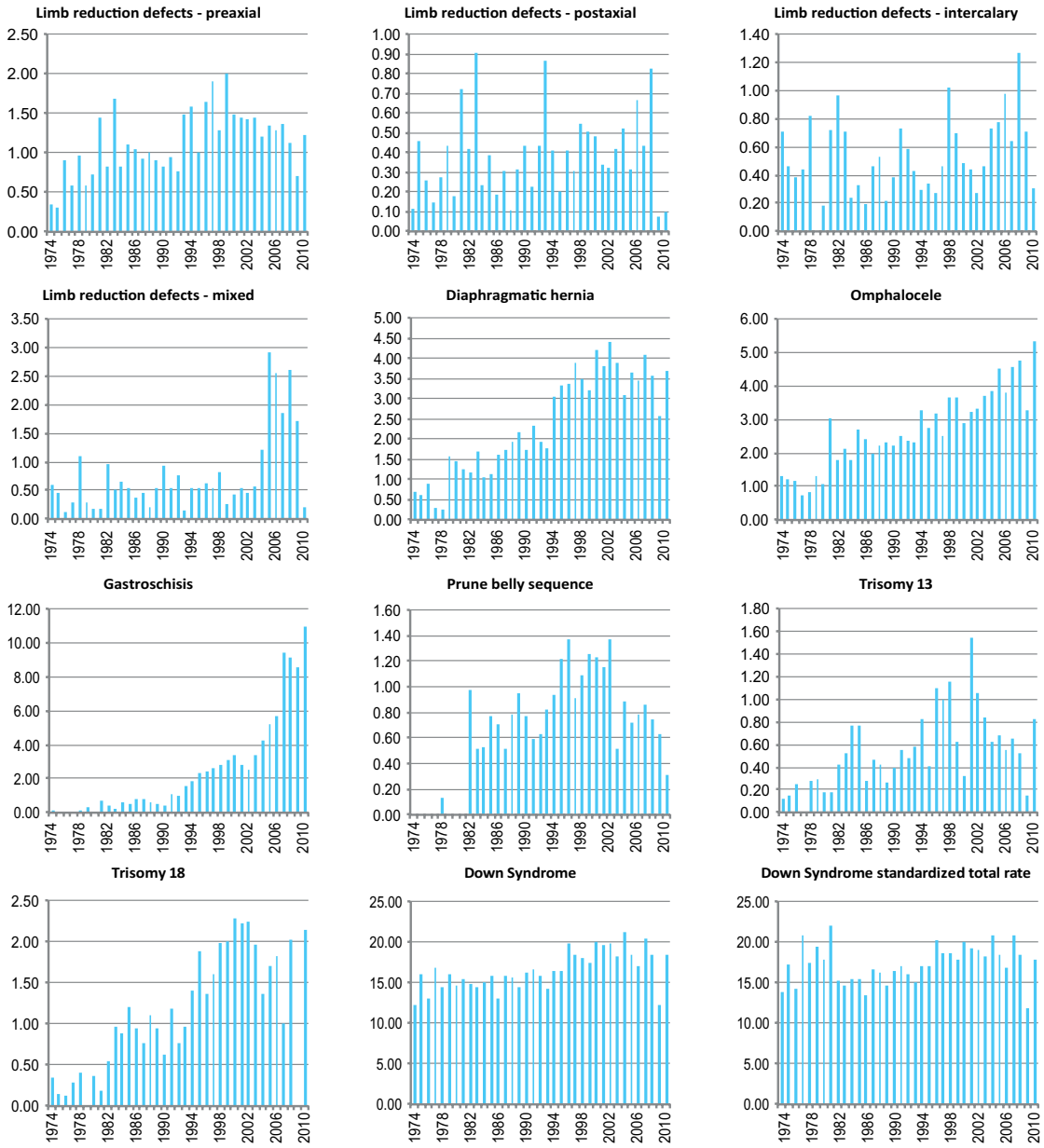
Note: L+S rates

South America: ECLAMC



Note: L+S rates

South America: ECLAMC



Note: L+S rates

Spain: ECEMC
Spanish Collaborative Study of Congenital Malformations

History:
The programme was created in 1976 by Prof. Dr. María Luisa Martínez-Frías, as a hospital-based case-control study and surveillance system. ECEMC joined ICBDSR in 1979. It is also a member of EUROCAT contributing with data since 1980. In January 2002, the ECEMC Programme started its activities into the CIAC (Research Center on Congenital Anomalies), of the Instituto de Salud Carlos III (ISCIII), now dependent from the Ministry of Economy and Competitiveness, of Spain. In 2006 the ECEMC was recognized as an excellence Research programme to be integrated into the CIBERER (Centre for Biomedical Research on Rare Diseases). ECEMC also operates two Teratogen Information Services (TIS) since 1991, one for the general population and another one for physicians. ECEMC and the two TIS are directed by Prof. Martínez-Frías. In June 2012, ECEMC's Clinical Network was formally constituted.

Size and coverage:
Data are obtained from about 70 hospitals distributed all over Spain. The annual number of births is about 90,000, representing near 20% of all Spanish births. Stillbirths of at least 24 weeks or 500 g. have been included since 1980. Data on terminations of pregnancy due to the presence of congenital anomalies, which can be legally performed under defined circumstances, can be gathered on a routine basis only in some participating hospitals.

Legislation and funding:
It is a research programme with voluntary participation of hospitals (but mandatory subjugation to the operating rules expressed in the Operating Manual, for those participating), and is financed mainly by the Spanish Administration and, partially, by non-governmental organisations. ECEMC has the approval of the Research Ethics Committee of ISCIII.

Sources of ascertainment:
The detection period comprises the first 3 days of life, including major and/or minor/mild defects. For some selected cases a longer follow-up can be performed. Controls are defined as the next non-malformed infant born at the same hospital that the case with the same sex as the malformed infant. The information comes from delivery units and paediatric departments of the participating hospitals. Mothers are interviewed directly by the participating physicians, during those first 3 days after infant's delivery, to fill in the ECEMC standard protocols, which include more than 310 data for each child, whether case or control. The information for each case and its control is gathered by the same physician after the written informed consent of parents. In many instances, photographs, imaging studies, high-resolution bands karyotypes and molecular analyses when needed (which are performed at the central group of the ECEMC), and other complementary studies are available. Biological samples are also stored in the ECEMC registry for those cases and controls for which the collaborating physicians send them, with the informed consent of the parents.

Exposure information:
The mother of each reported infant (case or control) is interviewed within the first three days after delivery to obtain data on several exposures (parental occupation, maternal acute or chronic diseases, drug usage, illicit drugs, alcohol and tobacco maternal consumption, exposure to other chemical or physical factors), apart from the other data gathered (family history, obstetrical and demographic data, paternal exposures among others). It is important to note that when the paediatricians detect the cases and select the control children, they are blinded to the different maternal and family data that they are going to collect.

Background information:
Total number of births by sex and number of twin pairs in each participating hospital are gathered. Other background information is obtained from the control material.

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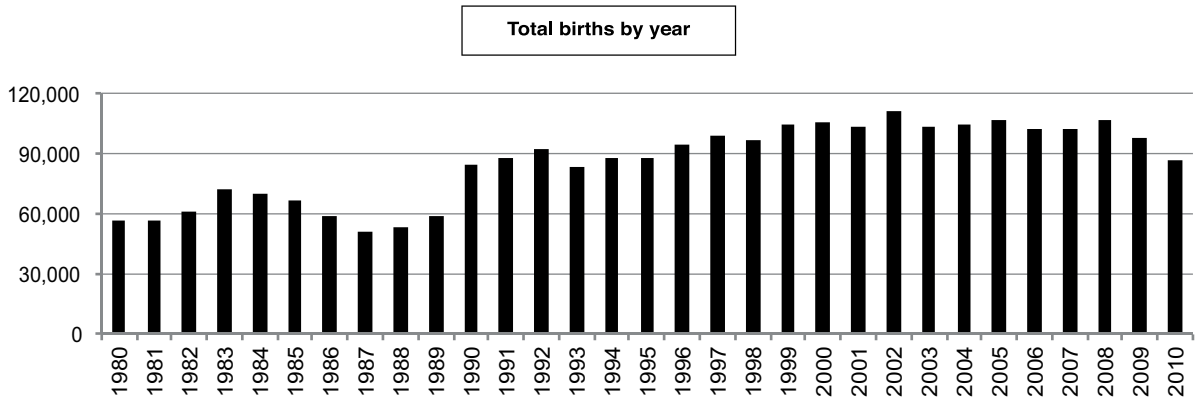
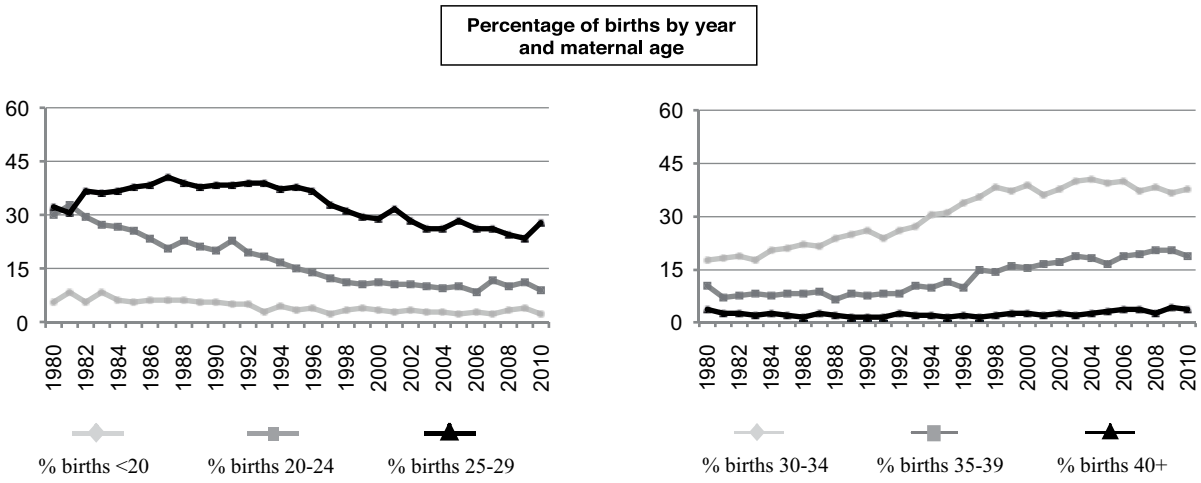
Spain: ECEMC


Total births by year
120,000
90,000
60,000
30,000
0
1980
1981
1982
1983
1984
1985
1986
1987
1988
1989
1990
1991
1992
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010


Percentage of births by year and maternal age
60
45
30
15
0
1980
1982
1984
1986
1988
1990
1992
1994
1996
1998
2000
2002
2004
2006
2008
2010
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Spain: ECEMC, 2010

Live births (LB)	86,784
Stillbirths (SB)	302
Total births	87,086
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	2	nr	0.23
Spina bifida	3	0	nr	0.34
Encephalocele	1	1	nr	0.23
Microcephaly	3	1	nr	0.46
Holoprosencephaly	3	0	nr	0.34
Hydrocephaly	17	2	nr	2.18
Anophthalmos	3	0	nr	0.34
Microphthalmos	7	0	nr	0.80
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	18	0	nr	2.07
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	3	0	nr	0.34
Tetralogy of Fallot	6	0	nr	0.69
Hypoplastic left heart syndrome	0	0	nr	0.00
Coarctation of aorta	4	0	nr	0.46
Choanal atresia, bilateral	1	0	nr	0.11
Cleft palate without cleft lip	23	0	nr	2.64
Cleft lip with or without cleft palate	27	0	nr	3.10
Oesophageal atresia/stenosis with or without fistula	7	0	nr	0.80
Small intestine atresia/stenosis	3	0	nr	0.34
Anorectal atresia/stenosis	11	0	nr	1.26
Undescended testis (36 weeks of gestation or later)	20	0	nr	2.30
Hypospadias	13	0	nr	1.49
Epispadias	1	0	nr	0.11
Indeterminate sex	5	0	nr	0.57
Renal agenesis	1	0	nr	0.11
Cystic kidney	13	0	nr	1.49
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	16	1	nr	1.95
Total Limb reduction defects (include unspecified)	29	0	nr	3.33
Transverse	16	0	nr	1.84
Preaxial	3	0	nr	0.34
Postaxial	1	0	nr	0.11
Intercalary	1	0	nr	0.11
Mixed	4	0	nr	0.46
Unspecified	4	0	nr	0.46
Diaphragmatic hernia	4	0	nr	0.46
Omphalocele	6	0	nr	0.69
Gastroschisis	2	1	nr	0.34
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	2	0	nr	0.23
Trisomy 13	2	0	nr	0.23
Trisomy 18	1	0	nr	0.11
Down syndrome, all ages (include age unknown)	62	1	nr	7.23
<20	1	0	nr	4.80
20-24	3	0	nr	3.79
25-29	2	0	nr	0.82
30-34	10	0	nr	3.03
35-39	29	0	nr	17.58
40-44	13	1	nr	47.64
45+	4	0	nr	126.98
unknown	0	0	nr	---

nr = not reported

Spain: ECEMC, Previous years rates 1980 - 2010

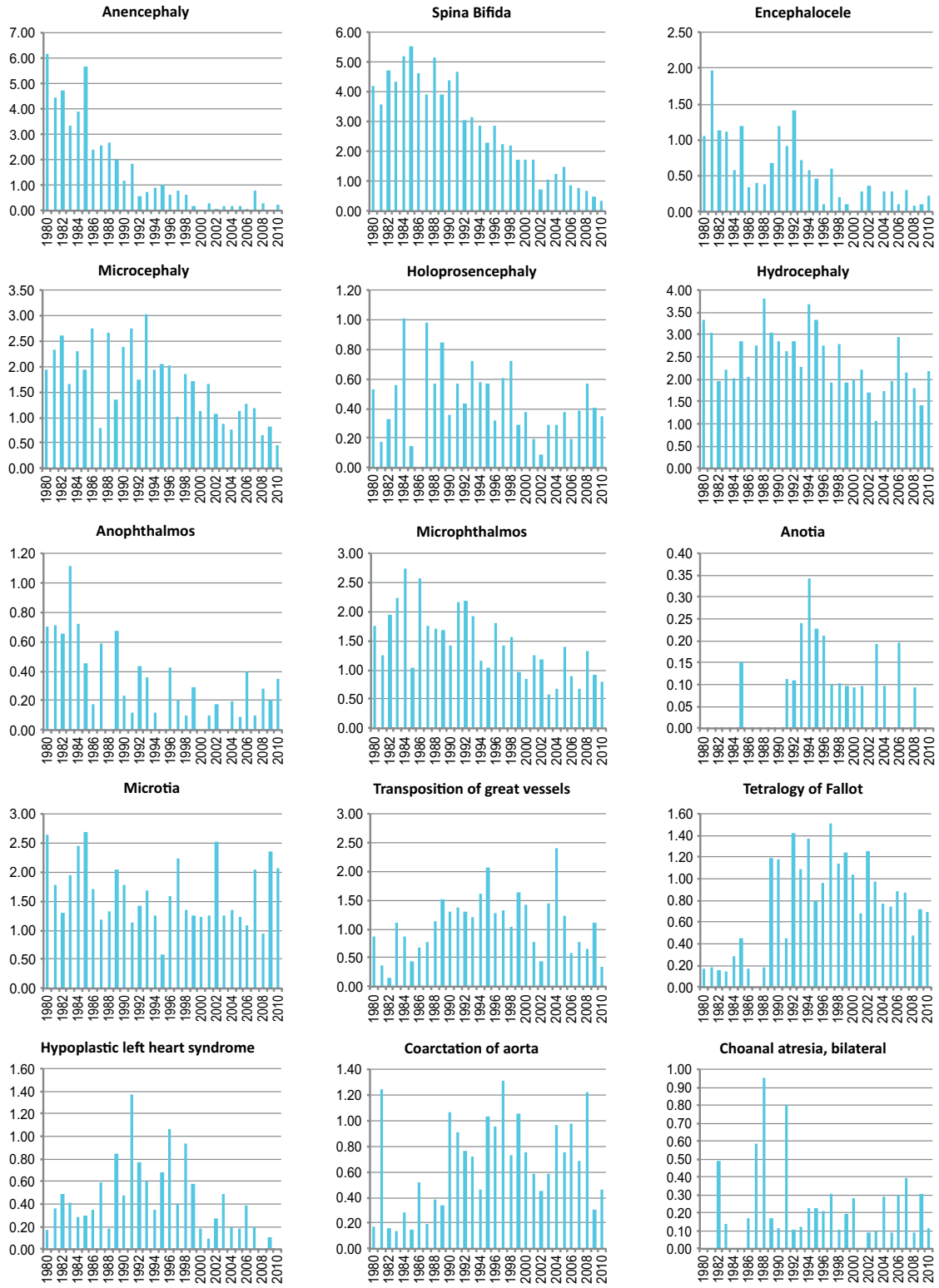
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980*	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**56,910**	**325,480**	**305,407**	**436,851**	**499,648**	**528,183**	**495,807**
Anencephaly	6.15	4.39	2.06	1.01	0.44	0.19	0.28
Spina bifida	4.22	4.70	4.39	3.20	2.12	1.25	0.65
Encephalocele	1.05	1.17	0.65	0.82	0.20	0.25	0.16
Microcephaly	1.93	2.15	2.03	2.29	1.54	1.10	0.89
Holoprosencephaly	0.53	0.46	0.52	0.57	0.46	0.25	0.38
Hydrocephaly	3.34	2.40	2.88	2.95	2.26	1.74	2.10
Anophthalmos	0.70	0.74	0.33	0.21	0.20	0.11	0.26
Microphthalmos	1.76	1.87	1.80	1.69	1.30	1.02	0.93
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.00	0.03	0.00	0.21	0.12	0.08	0.06
Microtia	2.64	2.06	1.64	1.21	1.52	1.53	1.67
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	0.88	0.61	1.11	1.51	1.34	1.25	0.71
Tetralogy of Fallot	0.18	0.25	0.62	1.03	1.18	0.89	0.73
Hypoplastic left heart syndrome	0.18	0.37	0.49	0.76	0.62	0.25	0.14
Coarctation of aorta	0.18	0.37	0.56	0.78	0.96	0.66	0.75
Choanal atresia, bilateral	0.00	0.12	0.36	0.30	0.22	0.11	0.24
Cleft palate without cleft lip	4.74	5.19	4.39	4.81	3.94	4.05	3.15
Cleft lip with or without cleft palate	5.27	5.87	5.14	5.91	4.14	3.67	3.11
Oesophageal atresia/stenosis with or without fistula	1.41	2.46	1.64	2.31	1.50	2.04	1.43
Small intestine atresia/stenosis	0.70	0.49	0.52	0.53	0.40	0.59	0.54
Anorectal atresia/stenosis	1.93	2.64	2.29	1.99	2.10	2.03	1.53
Undescended testis (36 weeks of gestation or later)	1.23	1.90	2.55	2.84	2.80	2.40	2.04
Hypospadias	2.81	2.70	2.13	2.04	1.70	2.12	1.47
Epispadias	0.18	0.22	0.23	0.16	0.08	0.09	0.08
Indeterminate sex	0.35	1.20	1.11	0.66	0.58	0.55	0.46
Renal agenesis	0.53	0.71	0.92	0.60	0.38	0.08	0.08
Cystic kidney	1.76	1.08	1.64	1.76	1.72	1.42	1.57
Bladder exstrophy	0.35	0.28	0.33	0.23	0.24	0.19	0.16
Polydactyly, preaxial	1.76	2.49	2.46	3.41	2.52	2.08	2.12
Total Limb reduction defects (include unspecified)	6.15	7.28	6.88	6.80	5.54	4.49	4.11
Transverse	2.46	3.01	3.05	2.40	2.38	1.74	1.69
Preaxial	0.53	1.29	1.05	0.89	0.66	0.59	0.56
Postaxial	0.00	0.18	0.16	0.23	0.20	0.09	0.10
Intercalary	0.18	0.61	0.16	0.64	0.20	0.30	0.16
Mixed	1.58	1.04	1.15	1.03	1.10	0.91	0.83
Unspecified	1.41	1.14	1.31	1.60	0.96	0.68	0.50
Diaphragmatic hernia	1.93	2.86	2.03	2.22	1.22	0.74	1.03
Omphalocele	2.46	1.57	1.34	1.19	0.70	0.59	0.52
Gastroschisis	0.53	0.55	0.43	0.30	0.50	0.28	0.75
Unspecified Omphalocele/Gastroschisis	0.18	0.37	0.36	0.14	0.06	0.02	0.02
Prune belly sequence	0.18	0.65	0.49	0.53	0.26	0.15	0.26
Trisomy 13	0.35	0.34	0.46	0.46	0.50	0.40	0.18
Trisomy 18	0.35	1.20	0.88	0.96	0.66	0.61	0.61
Down syndrome, all ages (include age unknown)	13.71	14.96	14.11	12.59	10.27	7.69	7.06
<20	3.06	7.65	9.16	6.84	1.73	2.56	5.78
20-24	8.15	6.22	6.37	5.32	3.71	5.34	4.74
25-29	5.43	6.60	7.93	7.55	6.05	4.28	2.84
30-34	9.97	12.36	13.16	13.58	9.86	7.15	4.90
35-39	36.66	48.39	39.05	35.42	20.85	12.28	12.33
40-44	96.48	175.25	154.51	60.08	53.43	35.83	32.00
45+	83.33	246.91	188.09	264.15	531.91	26.46	112.00
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 7 years

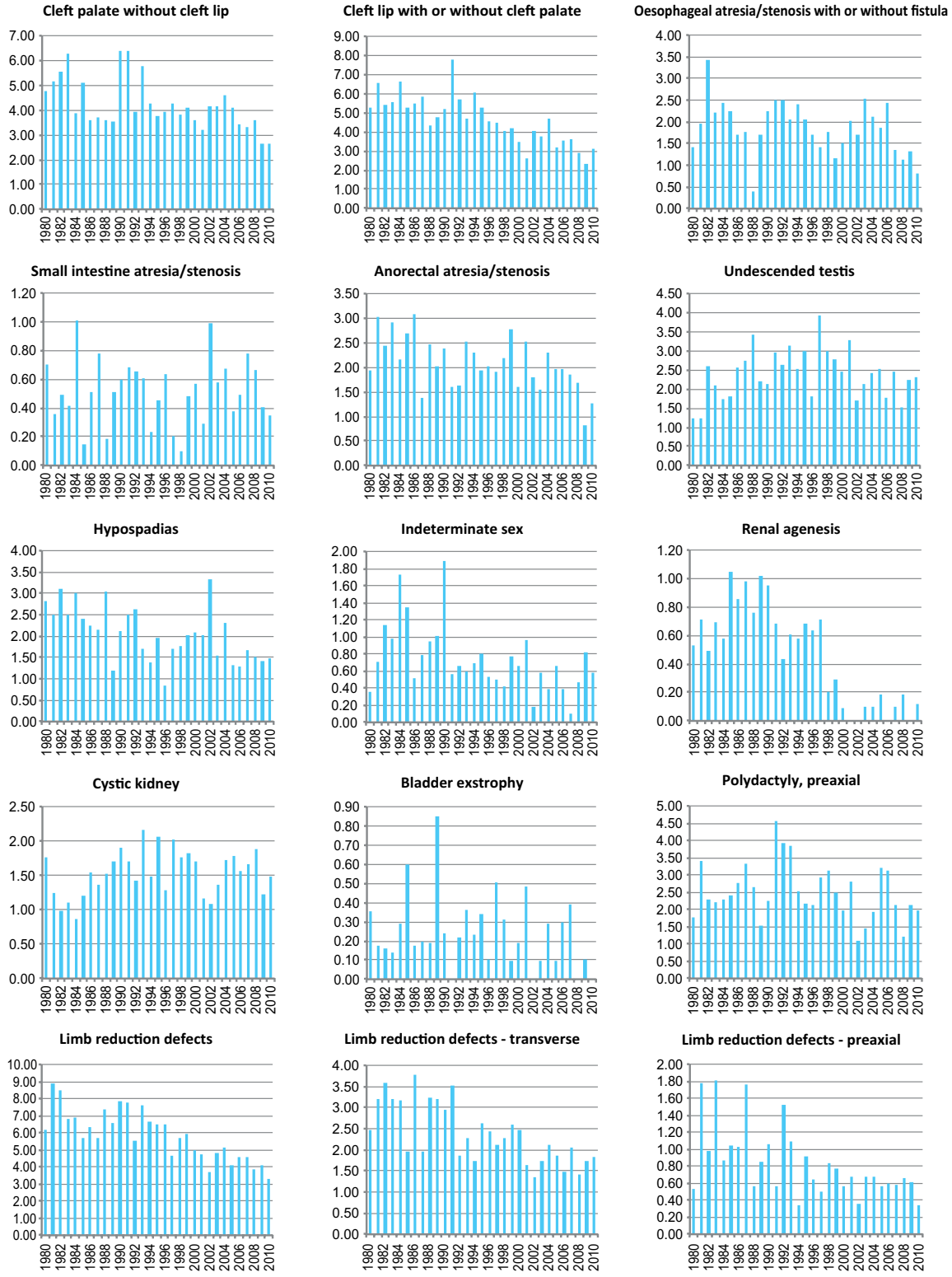
Spain: ECEMC

Time trends 1980-2010 (Birth prevalence rates per 10,000)



Note: L+S rates

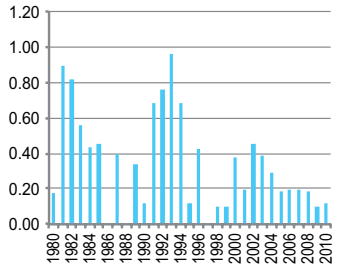
Spain: ECEMC



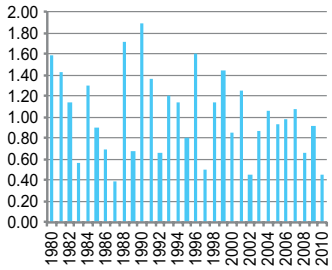
Note: L+S rates

Spain: ECEMC

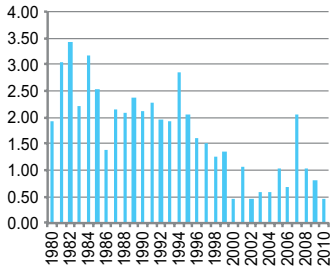
Limb reduction defects - intercalary



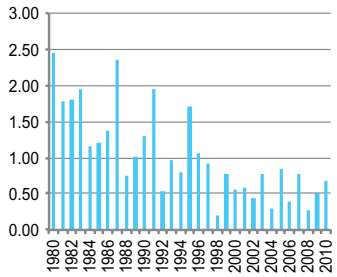
Limb reduction defects - mixed



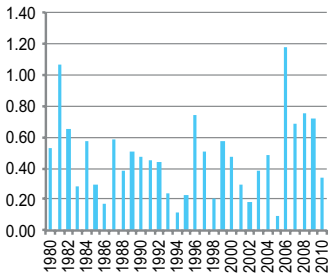
Diaphragmatic hernia



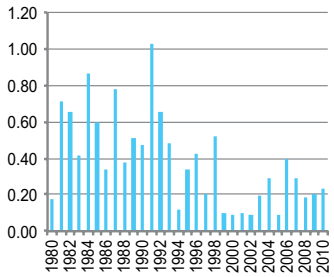
Omphalocele



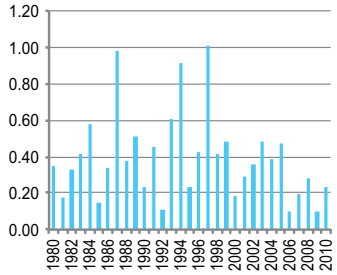
Gastroschisis



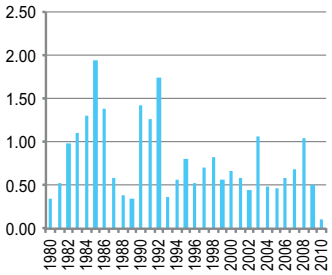
Prune belly sequence



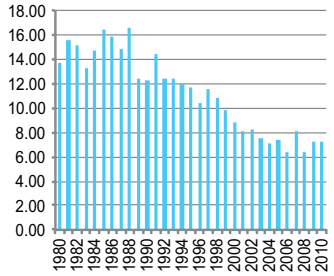
Trisomy 13



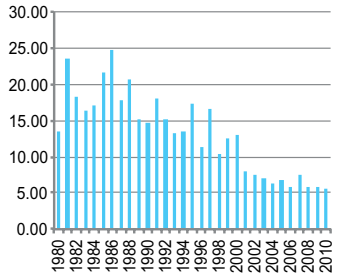
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Sweden

The Swedish Registry of Congenital Malformations and the Medical Birth Registry

History:
The Swedish Registry of Congenital Malformations started in 1964 and changed name to The Swedish Birth Defects Register in 2007. The Swedish Medical Registry started in 1973. The programme was a founding member of the ICBDSR and contributed with data until 1994. The register has a new regime from 1999 and is since then again a full member of the ICBDSR.

Size and coverage:
All births in Sweden are included, approximately 100,000 – 120,000 annual births. The definition of a child is all children born alive and foetal deaths after 22 weeks gestation. In 1999 a special fetal surveillance system was started to include those fetuses with congenital anomalies who were terminated as a result of prenatal diagnosis.

Legislation and funding:
Reporting of birth defects in live- and stillborn infants is compulsory. Reporting of terminated pregnancies because of birth defects of the fetuses is, however, not compulsory. The registers are run by and funded by the National Board of Health and Social Welfare (Govermental).

Sources of ascertainment:
Reports are received from delivery units, paediatric clinics, pathology departments, child cardiology clinics, and cytogenetic laboratories.

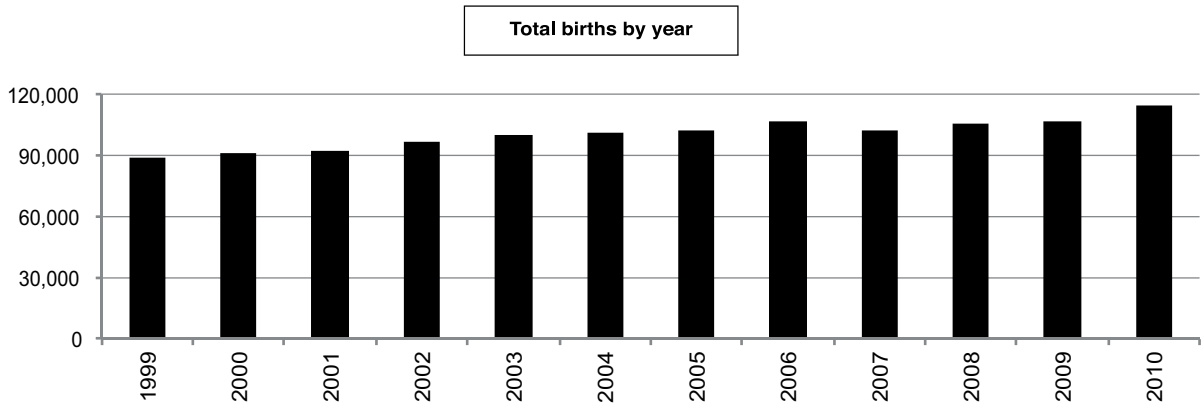
Exposure information:
Some exposure information for all births is available in the Medical Birth Registry: maternal occupation, civic status, maternal smoking, drug use during pregnancy, contraceptive usage, and maternal diseases.

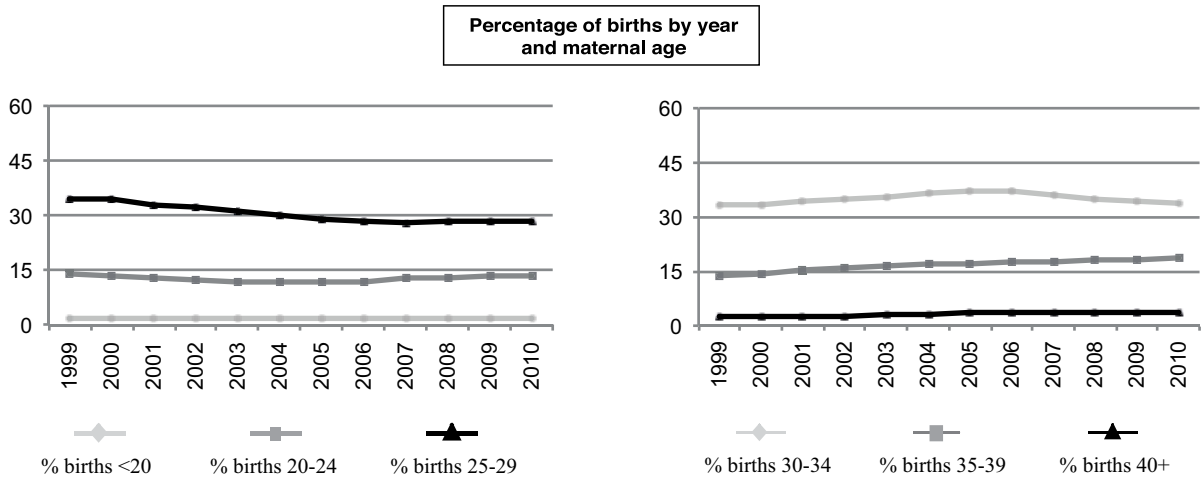
Background information:
Epidemiological background data are available on all birth in the Medical Birth Registry.

Addresses and Staff:

Karin Källén Ph.D., National Board of Health and Social Welfare, S-106 30 Stockholm, Sweden
Phone: 46-46-2227538
E-mail: karin.kallen@med.lu.se

Sweden





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	87	92.6	Cystic kidney	38	37.3
Spina bifida	75	60.5	Limb reduction defects	24	15.8
Encephalocele	21	70.0	Diaphragmatic hernia	35	38.9
Holoprosencephaly	14	77.8	Omphalocele	45	68.2
Hydrocephaly	50	58.8	Gastroschisis	12	22.6
Hypoplastic left heart syndrome	42	58.3	Trisomy 13	105	83.3
Cleft palate without cleft lip	7	3.9	Trisomy 18	244	83.6
Cleft lip with or without cleft palate	8	3.9	Down syndrome	642	59.1
Renal agenesis	31	50.0			

Total ToPs with births defects = 1,824 (Ratio ToPs/Births: 5.59 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Sweden, 2010

Live births (LB)	114,055
Stillbirths (SB)	425
Total births	114,480
Number of terminations of pregnancy (ToP) for birth defects	697

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	24	2.18
Spina bifida	7	1	25	2.88
Encephalocele	2	0	2	0.35
Microcephaly	8	0	0	0.70
Holoprosencephaly	0	0	3	0.26
Hydrocephaly	11	0	12	2.01
Anophthalmos	1	0	1	0.17
Microphthalmos	3	0	0	0.26
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	4	0	0	0.35
Microtia	5	0	0	0.44
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	26	0	3	2.53
Tetralogy of Fallot	33	0	5	3.32
Hypoplastic left heart syndrome	8	0	12	1.75
Coarctation of aorta	36	1	2	3.41
Choanal atresia, bilateral	4	0	1	0.44
Cleft palate without cleft lip	64	0	3	5.85
Cleft lip with or without cleft palate	1	15	0	1.40
Oesophageal atresia/stenosis with or without fistula	24	0	1	2.18
Small intestine atresia/stenosis	13	0	0	1.14
Anorectal atresia/stenosis	24	0	7	2.71
Undescended testis (36 weeks of gestation or later)	10	0	0	0.87
Hypospadias	286	0	0	24.98
Epispadias	5	0	0	0.44
Indeterminate sex	1	0	2	0.26
Renal agenesis	11	1	9	1.83
Cystic kidney	24	0	10	2.97
Bladder exstrophy	3	0	0	0.26
Polydactyly, preaxial	12	0	0	1.05
Total Limb reduction defects (include unspecified)	45	0	6	4.45
Transverse	15	0	2	1.48
Preaxial	0	0	1	0.09
Postaxial	1	0	0	0.09
Intercalary	4	0	0	0.35
Mixed	25	0	3	2.45
Unspecified	0	0	0	0.00
Diaphragmatic hernia	17	1	8	2.27
Omphalocele	9	0	9	1.57
Gastroschisis	16	0	3	1.66
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.09
Trisomy 13	7	0	37	3.84
Trisomy 18	16	3	124	12.49
Down syndrome, all ages (include age unknown)	165	2	255	36.86
<20	1	0	0	5.39
20-24	16	1	4	13.80
25-29	19	0	20	11.88
30-34	37	0	24	15.76
35-39	61	1	92	72.05
40-44	24	0	99	289.07
45+	4	0	15	791.67
unknown	3	0	1	---

Sweden, Previous years rates 1999 - 2010

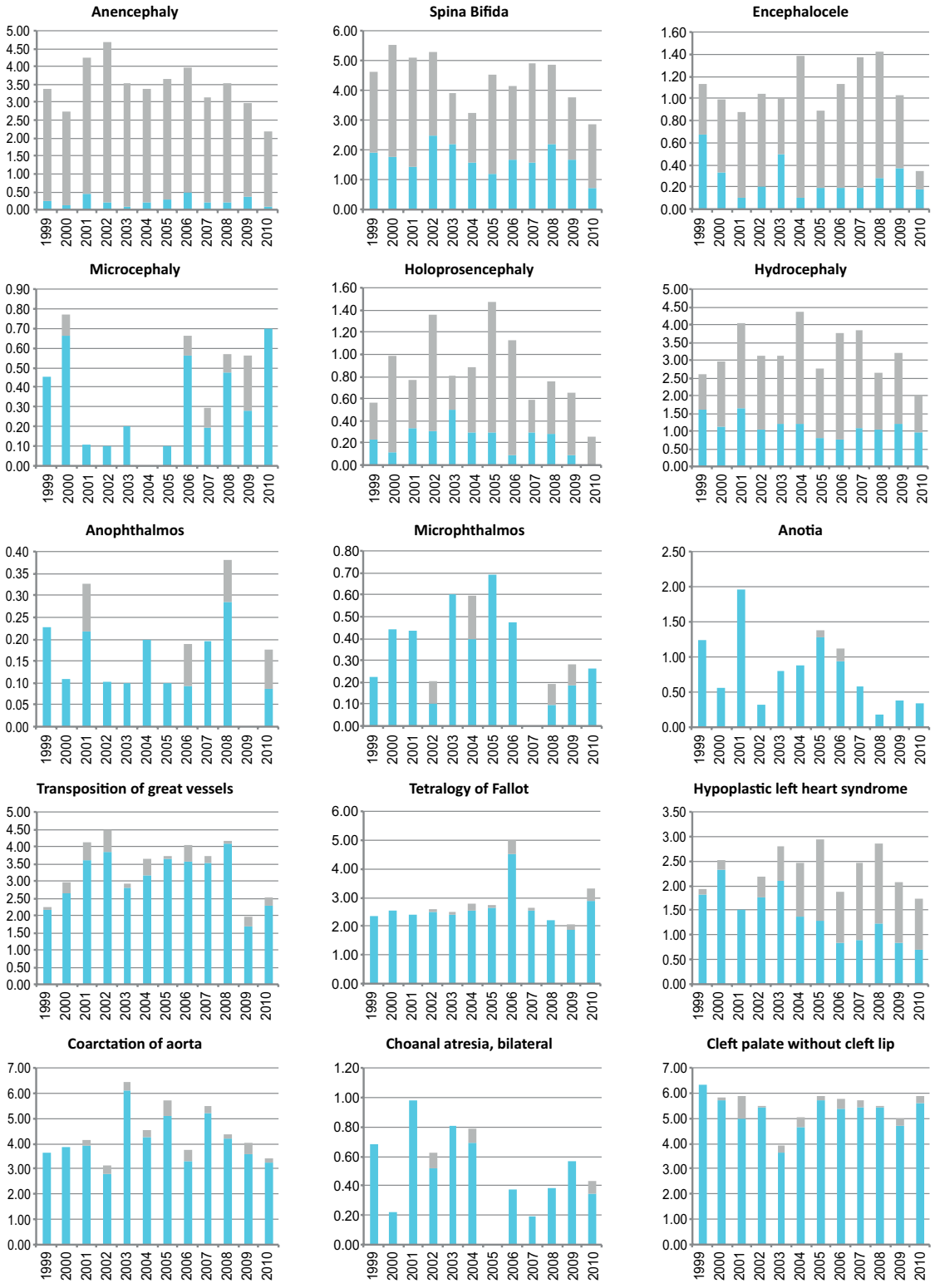
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000*	2001-2005	2006-2010
Total births					**179,308**	**490,406**	**534,416**
Anencephaly					3.07	3.87	3.14
Spina bifida					5.08	4.40	4.08
Encephalocele					1.06	1.04	1.05
Microcephaly					0.61	0.10	0.56
Holoprosencephaly					0.78	1.06	0.67
Hydrocephaly					2.79	3.47	3.07
Anophthalmos					0.17	0.16	0.19
Microphthalmos					0.33	0.51	0.24
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.07
Anotia					0.89	1.06	0.52
Microtia					0.06	0.14	0.30
Unspecified Anotia/Microtia					0.00	0.00	0.06
Transposition of great vessels					2.62	3.77	3.27
Tetralogy of Fallot					2.45	2.61	3.05
Hypoplastic left heart syndrome					2.23	2.41	2.19
Coarctation of aorta					3.74	4.81	4.19
Choanal atresia, bilateral					0.45	0.63	0.39
Cleft palate without cleft lip					6.08	5.24	5.56
Cleft lip with or without cleft palate					9.54	10.32	6.16
Oesophageal atresia/stenosis with or without fistula					1.84	2.69	2.43
Small intestine atresia/stenosis					2.12	2.71	1.80
Anorectal atresia/stenosis					2.84	3.04	2.88
Undescended testis (36 weeks of gestation or later)					nr	nr	0.40*
Hypospadias					19.46	20.60	23.50
Epispadias					0.06	0.22	0.28
Indeterminate sex					0.28	0.24	0.19
Renal agenesis					2.45	1.39	1.83
Cystic kidney					2.51	3.63	3.31
Bladder exstrophy					0.22	0.27	0.28
Polydactyly, preaxial					3.51	4.89	2.49
Total Limb reduction defects (include unspecified)					4.35	5.14	4.90
Transverse					2.45	3.57	3.05
Preaxial					0.33	0.29	0.43
Postaxial					0.22	0.12	0.17
Intercalary					0.11	0.24	0.28
Mixed					1.23	0.51	1.03
Unspecified					0.00	0.00	1.09
Diaphragmatic hernia					2.79	2.81	2.96
Omphalocele					2.23	2.92	2.02
Gastroschisis					2.01	1.81	1.65
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00
Prune belly sequence					0.06	0.12	0.21
Trisomy 13					2.01	2.57	3.46
Trisomy 18					5.47	6.75	9.09
Down syndrome, all ages (include age unknown)					21.81	25.77	30.84
<20					8.76	8.47	10.06
20-24					9.37	8.66	8.34
25-29					6.34	9.56	10.37
30-34					14.71	18.35	16.49
35-39					51.25	56.13	60.25
40-44					161.92	177.40	227.81
45+					421.05	477.88	735.61
unknown					---	---	---

nr = not reported
* data include less than 5 years

Sweden

Time trends 1999-2010 (Birth prevalence rates per 10,000)



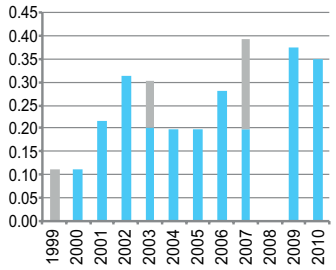
Note: L+S rates, ToP rates

Sweden

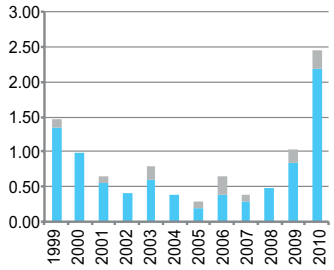
Note: L+S rates, ToP rates

Sweden

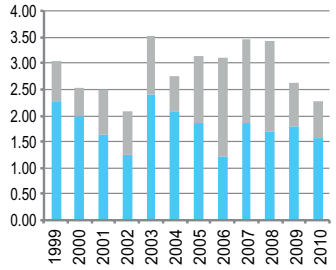
Limb reduction defects - intercalary



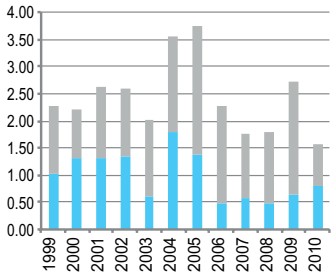
Limb reduction defects - mixed



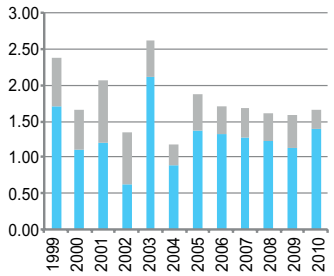
Diaphragmatic hernia



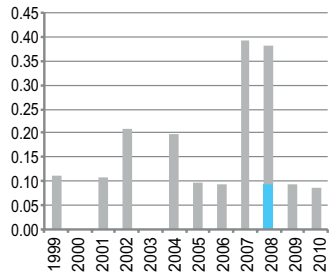
Omphalocele



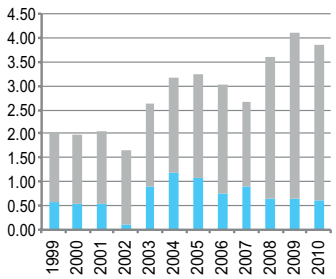
Gastroschisis



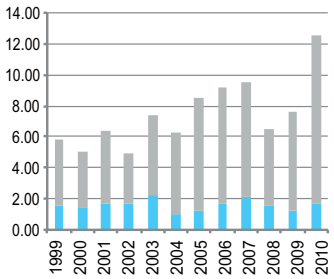
Prune belly sequence



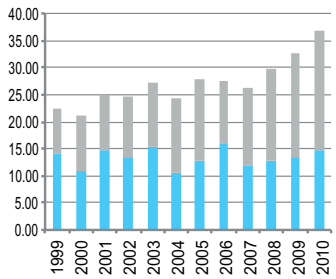
Trisomy 13



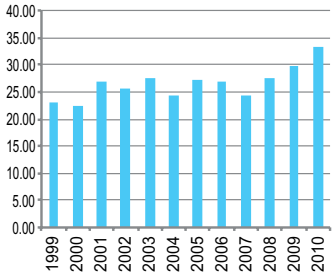
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Ukraine: OMNI-Net
Ukraine Birth Defects Program

History:
Population based birth defects surveillance began in 2000 in the framework of the Ukrainian-American Birth Defects Program (UABDP) funded by the United States Agency for International Development (USAID). The program became an associate member of ICBDSR in 2001. In 2005 the USAID component was completed and the program was assumed by OMNI-Net, a not-for-profit international organization incorporated in Ukraine, and is continued as OMNI-Net Ukraine Birth Defects Program. OMNI-Net represents five resource OMNI-Centers all of which provide care for children with birth defects, promote prevention programs, participate in parental organizations and engage in collaborative programs with national and international partners.

Program objectives include universal folic acid flour fortification, methods to reduce alcohol impact on child development in collaboration with partners and promoting international partnerships.

Legislation and funding:
OMNI-Net personnel are financed from regional budgets. The legislation and rules by the Ministry of Health mandates the reporting of birth defects. BD data is reported by Oblast Vital Statistics Centrum who aggregates, formats and forwards the data to the Ministry of Health.

Population Coverage:
BD surveillance annually covers about 30000 births in two oblasts (provinces) of Northwestern Ukraine – Rivne and Volyn, representing approximately 6% of births in Ukraine. The population is relatively homogeneous and stable (data is pooled from these two oblasts). The northern counties (rayons) of both oblasts are contaminated from Chornobyl disaster.

Sources of ascertainment:
Relevant hospital admission/discharge summaries are systematically reviewed. Qualified Registry specialists also routinely review all medical records of regional pediatric cardiology centres and obtain ascertainment of diagnostic details. Data from specialty clinics, laboratories (including cytogenetic one) and other services are explored. Our cytogenetic laboratories are the only ones in the region and they provide us with study reports. Pregnancy, obstetrics, delivery, neonatal and pediatrics records are reviewed. The information is substantial regarding service providers located in regional centres, but limited regarding service providers in rural environments.

Maximum Age at Diagnosis:
Up to 1 year of age.

Exposure information:
Routine information collection is limited except when ad hoc circumstances are noted. An expansion of exposure data collection is in progress.

Prenatal diagnosis information:
The information is substantial regarding service providers located in regional centers, but limited regarding service providers in rural environment.

Background information.
Data regarding ionizing radiation pollution in contaminated rayons is available by special agreements. Data from a population based neonatal registry is also available by special agreements.

Addresses and Staff:
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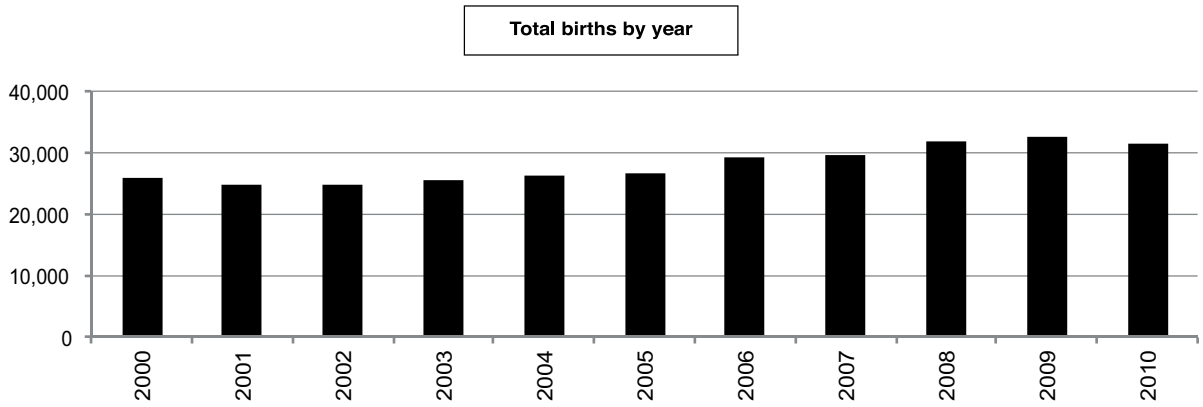
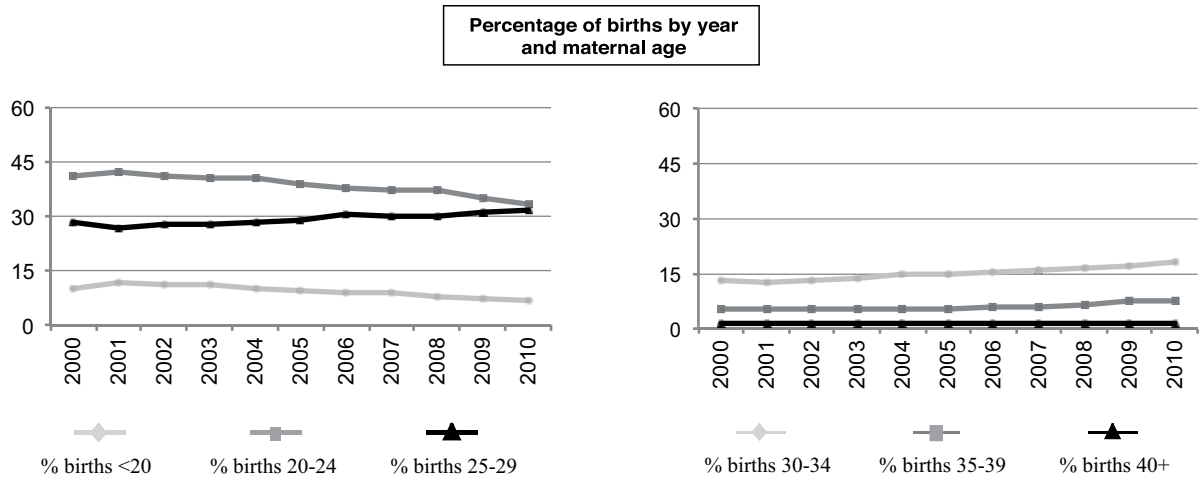
Medical Coordinator: Dr. Lyubov Yevtushok
"OMNI-Net for Children", 36, 16 Lypnya Str., Room 709, Rivne, Ukraine 33028
Phone/Fax: 38 036 262 3447
E-mail: werteleckiomni@gmail.com
yevtushokl@gmail.com
rivneomni2@gmail.com
Website: http://www.ibis-birthdefects.org/

Ukraine: OMNI-Net





Ukraine: OMNI-Net, 2010

Live births (LB)	31,381
Stillbirths (SB)	165
Total births	31,546
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	6	9	5.39
Spina bifida	21	1	16	12.05
Encephalocele	2	0	2	1.27
Microcephaly	20	2	nr	6.97
Holoprosencephaly	0	0	nr	0.00
Hydrocephaly	9	2	nr	3.49
Anophthalmos	0	0	nr	0.00
Microphthalmos	2	0	nr	0.63
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	1	0	nr	0.32
Microtia	5	0	nr	1.58
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	20	0	nr	6.34
Tetralogy of Fallot	8	0	nr	2.54
Hypoplastic left heart syndrome	2	1	nr	0.95
Coarctation of aorta	1	0	nr	0.32
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	25	0	nr	7.92
Cleft lip with or without cleft palate	29	0	nr	9.19
Oesophageal atresia/stenosis with or without fistula	8	0	nr	2.54
Small intestine atresia/stenosis	3	0	nr	0.95
Anorectal atresia/stenosis	3	1	nr	1.27
Undescended testis (36 weeks of gestation or later)	112	0	nr	35.50
Hypospadias	6	0	nr	1.90
Epispadias	1	0	nr	0.32
Indeterminate sex	1	0	nr	0.32
Renal agenesis	1	2	nr	0.95
Cystic kidney	11	1	nr	3.80
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	7	0	nr	2.22
Total Limb reduction defects (include unspecified)	17	0	nr	5.39
Transverse	16	0	nr	5.07
Preaxial	0	0	nr	0.00
Postaxial	0	0	nr	0.00
Intercalary	1	0	nr	0.32
Mixed	0	0	nr	0.00
Unspecified	0	0	nr	0.00
Diaphragmatic hernia	8	1	nr	2.85
Omphalocele	6	0	nr	1.90
Gastroschisis	3	1	nr	1.27
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13	0	0	nr	0.00
Trisomy 18	1	1	nr	0.63
Down syndrome, all ages (include age unknown)	50	1	nr	16.17
<20	2	0	nr	9.20
20-24	8	0	nr	7.62
25-29	15	0	nr	14.90
30-34	7	0	nr	12.04
35-39	12	0	nr	48.62
40-44	6	1	nr	138.07
45+	0	0	nr	0.00
unknown	0	0	nr	---

nr = not reported

Ukraine: OMNI-Net, Previous years rates 2000 - 2010

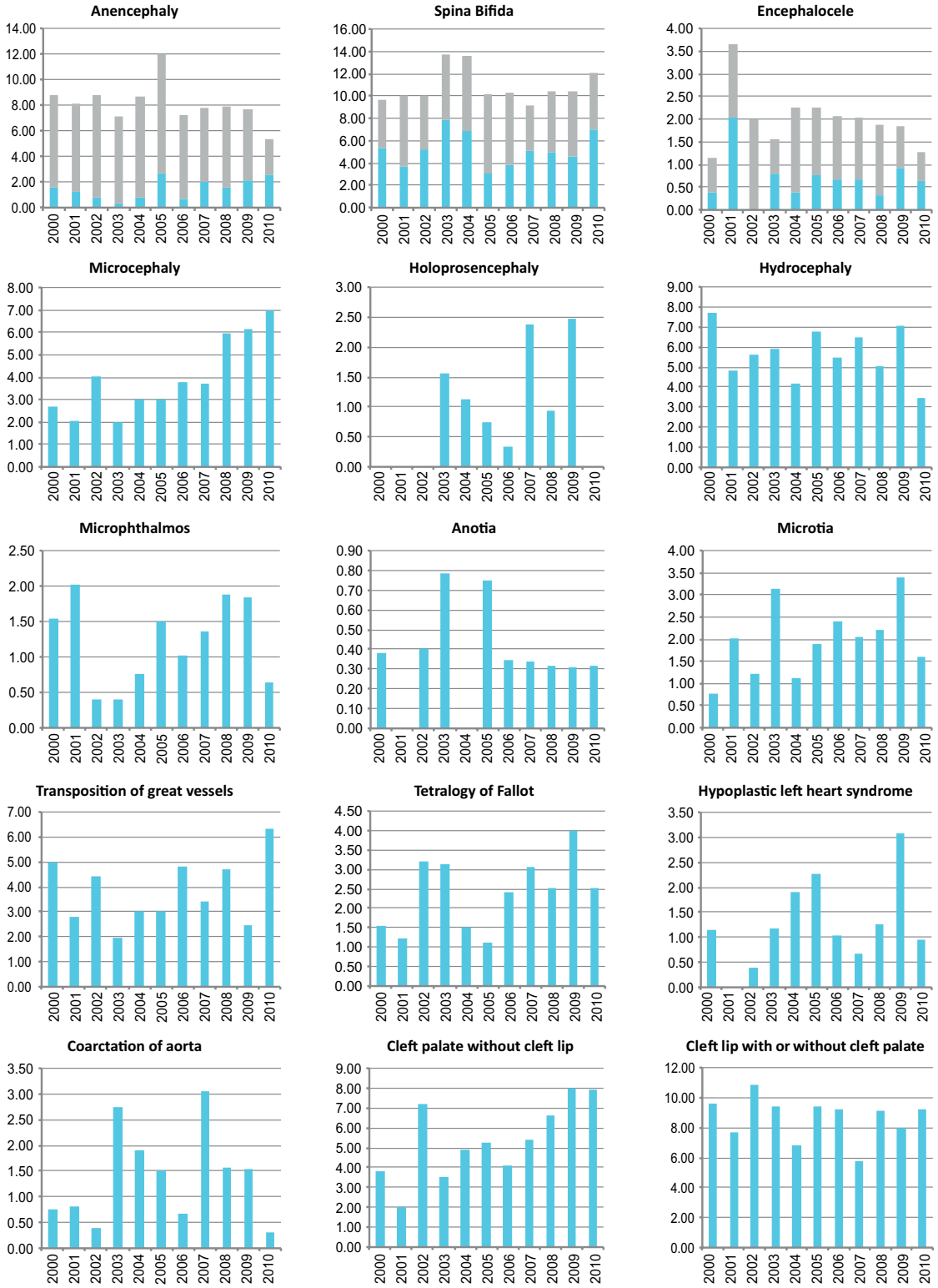
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000*	2001-2005	2006-2010
Total births					**26,025**	**128,135**	**154,539**
Anencephaly					8.84	8.97	7.18
Spina bifida					9.61	11.55	10.48
Encephalocele					1.15	2.34	1.81
Microcephaly					2.69	2.81	5.37
Holoprosencephaly					0.00	0.70	1.23
Hydrocephaly					7.68	5.46	5.50
Anophthalmos					0.38	0.00	0.19
Microphthalmos					1.54	1.01	1.36
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.06
Anotia					0.38	0.39	0.32
Microtia					0.77	1.87	2.33
Unspecified Anotia/Microtia					0.00	0.00	0.00
Transposition of great vessels					5.00	3.04	4.34
Tetralogy of Fallot					1.54	2.03	2.91
Hypoplastic left heart syndrome					1.15	1.17	1.42
Coarctation of aorta					0.77	1.48	1.42
Choanal atresia, bilateral					0.00	0.00	0.06
Cleft palate without cleft lip					3.84	4.60	6.47
Cleft lip with or without cleft palate					9.61	8.82	8.28
Oesophageal atresia/stenosis with or without fistula					2.31	1.64	2.26
Small intestine atresia/stenosis					1.54	1.56	1.49
Anorectal atresia/stenosis					1.92	2.73	1.81
Undescended testis (36 weeks of gestation or later)					34.58	41.60	32.29
Hypospadias					3.07	3.28	3.04
Epispadias					0.77	0.16	0.13
Indeterminate sex					0.77	0.39	0.32
Renal agenesis					0.77	0.86	0.78
Cystic kidney					1.54	2.42	4.46
Bladder exstrophy					1.15	0.70	0.52
Polydactyly, preaxial					3.07	3.04	4.40
Total Limb reduction defects (include unspecified)					4.23	3.28	4.34
Transverse					1.54	2.03	2.78
Preaxial					0.77	0.47	0.39
Postaxial					0.77	0.16	0.32
Intercalary					0.38	0.23	0.32
Mixed					0.38	0.16	0.45
Unspecified					0.38	0.23	0.00
Diaphragmatic hernia					2.31	1.72	2.78
Omphalocele					1.15	1.40	1.94
Gastroschisis					1.15	1.33	1.55
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00
Prune belly sequence					0.00	0.00	0.00
Trisomy 13					0.00	0.39	0.19
Trisomy 18					1.15	0.23	0.39
Down syndrome, all ages (include age unknown)					10.76	12.64	13.78
<20					11.23	10.09	8.13
20-24					4.64	6.90	7.51
25-29					6.76	9.47	10.07
30-34					17.60	16.41	13.98
35-39					22.34	35.80	38.26
40-44					147.42	98.21	143.82
45+					0.00	851.06	322.58
unknown					---	---	---

* data include less than 5 years

Ukraine: OMNI-Net

Time trends 2000-2010 (Birth prevalence rates per 10,000)

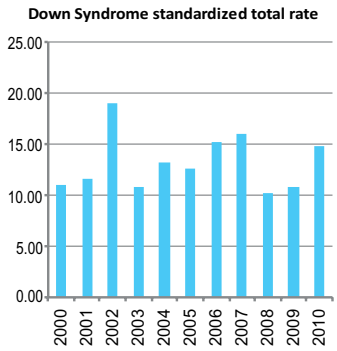


Note: L+S rates, ToP rates

Ukraine: OMNI-Net

Note: L+S rates, ToP rates

Ukraine: OMNI-Net



Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS

Congenital Anomaly Register and Information System for Wales

History:
CARIS aims to describe the pattern of congenital anomalies in Wales and provide:

- a description of anomalies and rates
- an assessment of antenatal detection and interventions
- information for health care planning
- identification of clusters and causes

Start of data collection: 1.1.1998. ICBDSR member: 2004. EUROCAT member: 1998.
Funding: Public Health Wales. Base: Singleton Hospital, Swansea

Population Coverage:
All pregnancies of mothers normally resident in Wales. This includes spontaneous fetal losses and terminations of pregnancy. Annual live birth rate of 35,000

Sources of Ascertainment:
Voluntary reporting
Mutiple source reporting including inpatient data
Clinical obstetric and paediatric champion in each delivery unit
Data coordinator in each delivery unit
Data exchange with bordering registers in England

Termination of Pregnancy:
Legal up to 24 weeks gestation in any pregnancy but no upper age limit for cases of major anomaly

Stillbirth Definition and Early Fetal Deaths:
Stillbirth = fetal death at or after 24 weeks gestation. No lower limit for inclusion of spontaneous fetal losses

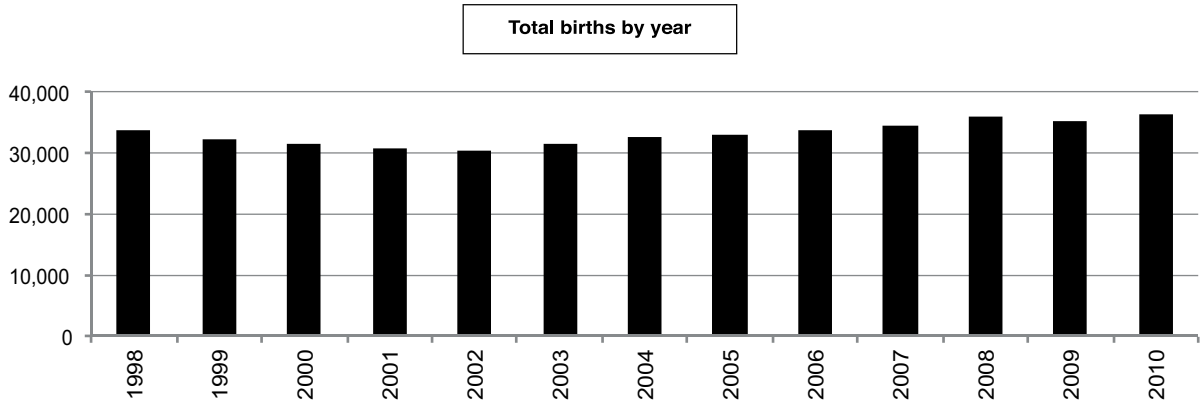
Exposure Data Availability:
Maternal drugs, folic acid dosage and timing, maternal and paternal diseases and occupations

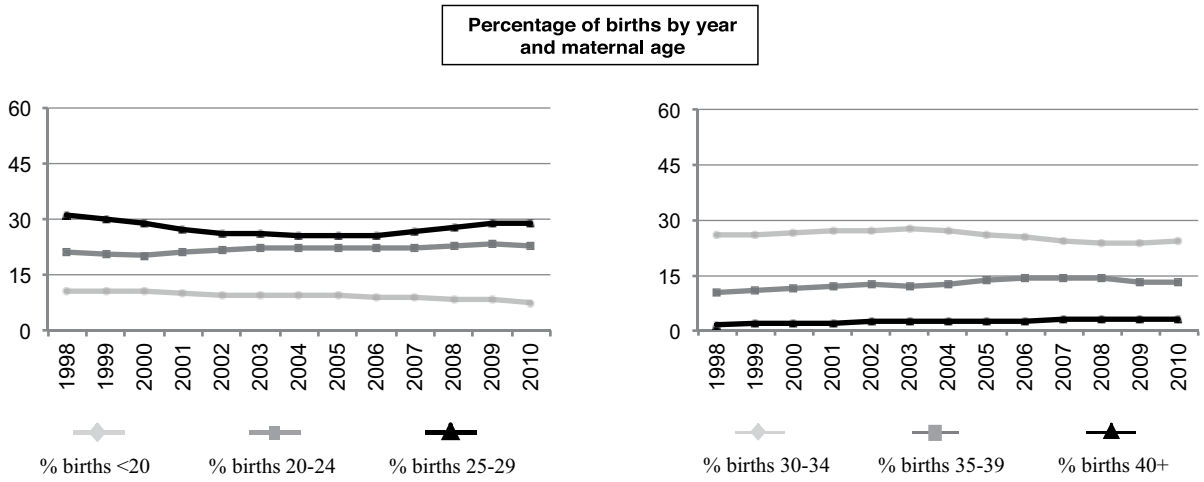
Denominators and Controls Information:
Data obtained from Office for National Statistics

Address and Staff:
Margery Morgan, Programme Director
Congenital Anomaly Register and Information Service for Wales (CARIS)
Public Health Wales
Singleton Hospital
Sketty Lane
Swansea, Wales, UK, SA2 8QA
Phone: 44-1792-285241
Fax: 44-1792-285241

Relevant Contact Person: David Tucker
E-mail: david.tucker2@wales.nhs.uk

United Kingdom-Wales: CARIS





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	53	100.0	Cystic kidney	17	20.2
Spina bifida	47	61.0	Limb reduction defects	33	37.5
Encephalocele	21	84.0	Diaphragmatic hernia	11	26.2
Holoprosencephaly	11	91.7	Omphalocele	23	57.5
Hydrocephaly	36	43.9	Gastroschisis	4	6.7
Hypoplastic left heart syndrome	11	40.7	Trisomy 13	19	90.5
Cleft palate without cleft lip	9	10.8	Trisomy 18	50	74.6
Cleft lip with or without cleft palate	21	17.1	Down syndrome	98	44.3
Renal agenesis	15	88.2			

Total ToPs with births defects = 521 (Ratio ToPs/Births: 4.87 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

United Kingdom-Wales: CARIS, 2010

Live births (LB)	35,952
Stillbirths (SB)	190
Total births	36,142
Number of terminations of pregnancy (ToP) for birth defects	164

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP (*)	Total rate
Anencephaly	0	0	13	3.60
Spina bifida	13	0	19	8.85
Encephalocele	≤ 3	0	8	nc
Microcephaly	15	0	0	4.15
Holoprosencephaly	0	0	≤ 3	nc
Hydrocephaly	17	0	6	6.36
Anophthalmos	0	0	0	0.00
Microphthalmos	4	0	0	1.11
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.83
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	14	≤ 3	≤ 3	nc
Tetralogy of Fallot	19	0	0	5.26
Hypoplastic left heart syndrome	≤ 3	0	4	nc
Coarctation of aorta	14	0	0	3.87
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	26	≤ 3	≤ 3	nc
Cleft lip with or without cleft palate	24	0	6	8.30
Oesophageal atresia/stenosis with or without fistula	7	≤ 3	0	nc
Small intestine atresia/stenosis	4	0	0	1.11
Anorectal atresia/stenosis	9	≤ 3	≤ 3	nc
Undescended testis (36 weeks of gestation or later)	38	0	0	10.51
Hypospadias	78	0	0	21.58
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	≤ 3	nc
Renal agenesis	0	0	6	1.66
Cystic kidney	23	0	4	7.47
Bladder exstrophy	≤ 3	0	≤ 3	nc
Polydactyly, preaxial	≤ 3	0	0	nc
Total Limb reduction defects (include unspecified)	16	0	7	6.36
Transverse	10	0	≤ 3	nc
Preaxial	≤ 3	0	≤ 3	nc
Postaxial	0	0	0	0.00
Intercalary	≤ 3	0	≤ 3	nc
Mixed	≤ 3	0	≤ 3	nc
Unspecified	≤ 3	0	0	nc
Diaphragmatic hernia	8	0	6	3.87
Omphalocele	5	0	6	3.04
Gastroschisis	19	0	≤ 3	nc
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	5	1.38
Trisomy 18	5	0	18	6.36
Down syndrome, all ages (include age unknown)	41	≤ 3	28	nc
<20	≤ 3	0	0	nc
20-24	≤ 3	≤ 3	≤ 3	nc
25-29	7	0	5	11.51
30-34	7	0	7	15.86
35-39	14	0	5	40.52
40-44	9	0	7	154.74
45+	0	0	≤ 3	nc
unknown	0	0	0	---

nc = not calculable
According to national guidelines, number for LB, SB and ToPs ≤3 not explicitly published

United Kingdom-Wales: CARIS, Previous years rates 1998 - 2010

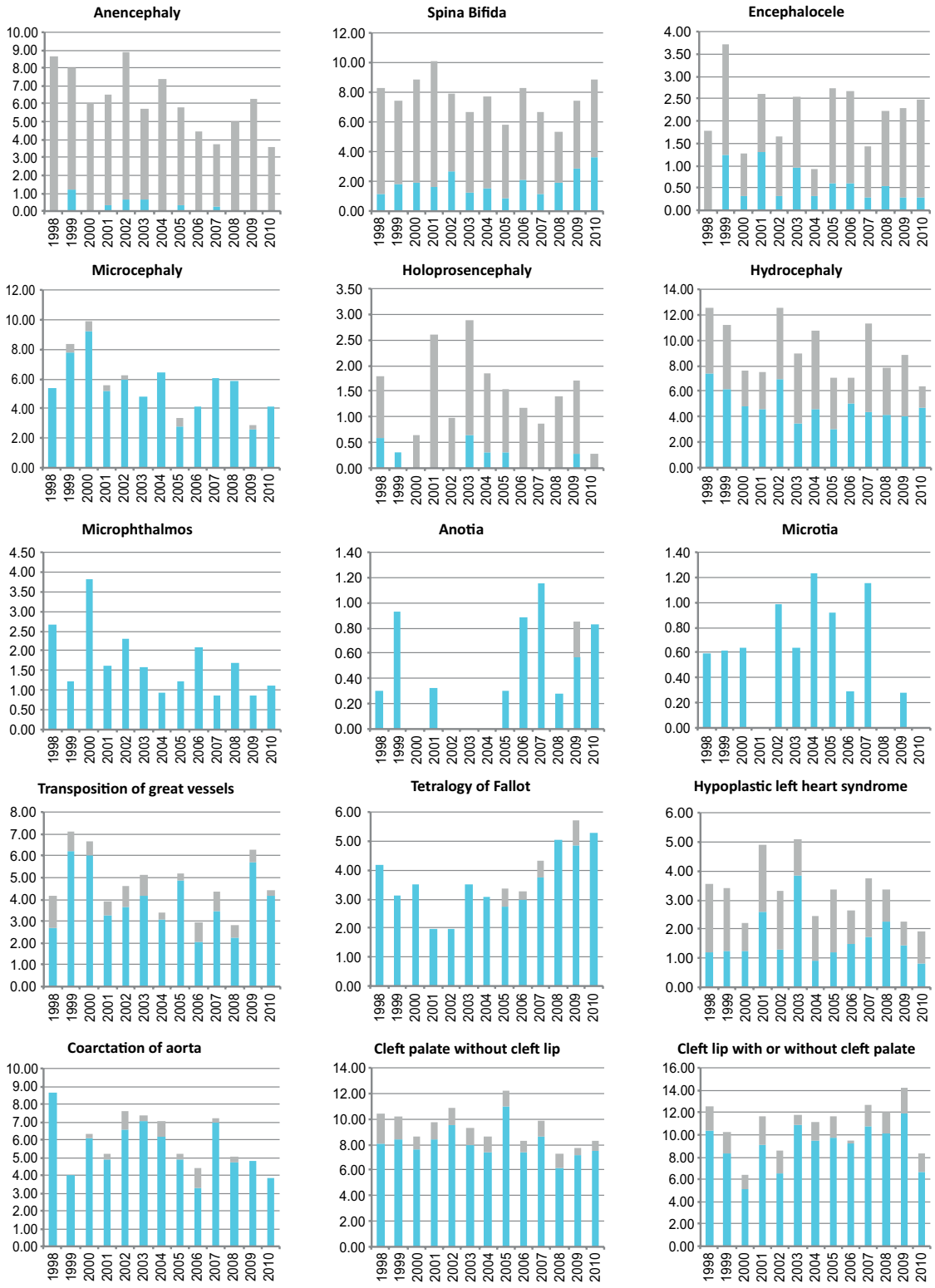
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000*	2001-2005	2006-2010
Total births					**97,335**	**157,728**	**175,423**
Anencephaly					7.60	6.85	4.62
Spina bifida					8.22	7.61	7.30
Encephalocele					2.26	2.09	2.22
Microcephaly					7.81	5.26	4.62
Holoprosencephaly					0.92	1.97	1.08
Hydrocephaly					10.48	9.32	8.27
Anophthalmos					0.62	0.25	0.11
Microphthalmos					2.57	1.52	1.31
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00
Anotia					0.41	0.13	0.80
Microtia					0.62	0.76	0.34
Unspecified Anotia/Microtia					0.00	0.00	0.00
Transposition of great vessels					5.96	4.44	4.16
Tetralogy of Fallot					3.60	2.79	4.73
Hypoplastic left heart syndrome					3.08	3.80	2.79
Coarctation of aorta					6.37	6.47	5.07
Choanal atresia, bilateral					0.21	0.19	0.23
Cleft palate without cleft lip					9.76	10.14	8.27
Cleft lip with or without cleft palate					9.76	10.97	11.34
Oesophageal atresia/stenosis with or without fistula					3.39	3.49	2.62
Small intestine atresia/stenosis					2.26	1.52	1.94
Anorectal atresia/stenosis					5.14	3.68	4.05
Undescended testis (36 weeks of gestation or later)					24.86	11.41	15.85
Hypospadias					30.31	29.67	27.88
Epispadias					0.51	0.44	0.11
Indeterminate sex					0.31	0.63	0.80
Renal agenesis					3.18	1.97	1.77
Cystic kidney					10.48	9.89	8.72
Bladder exstrophy					0.41	0.19	0.51
Polydactyly, preaxial					0.72	1.46	0.74
Total Limb reduction defects (include unspecified)					11.20	9.13	8.84
Transverse					5.03	4.44	4.73
Preaxial					1.95	1.01	1.60
Postaxial					0.82	0.32	0.23
Intercalary					1.23	1.97	1.20
Mixed					0.92	1.08	0.68
Unspecified					1.23	1.08	0.51
Diaphragmatic hernia					3.70	3.68	3.99
Omphalocele					2.88	4.56	3.93
Gastroschisis					4.73	6.15	6.10
Unspecified Omphalocele/Gastroschisis					0.41	0.70	0.23
Prune belly sequence					0.21	0.13	0.11
Trisomy 13					2.36	2.47	1.82
Trisomy 18					4.31	5.45	6.21
Down syndrome, all ages (include age unknown)					19.73	21.43	21.43
<20					11.60	6.50	7.40
20-24					7.48	6.90	10.70
25-29					10.57	11.90	7.84
30-34					18.94	15.75	18.49
35-39					56.48	56.86	54.37
40-44					142.21	173.41	140.70
45+					250.00	423.28	193.80
unknown					---	---	---

* data include less than 5 years

United Kingdom-Wales: CARIS

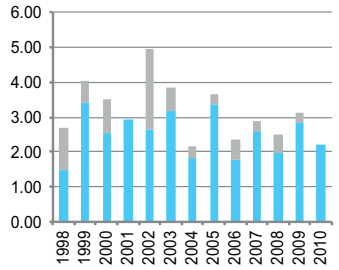
Time trends 1998-2010 (Birth prevalence rates per 10,000)



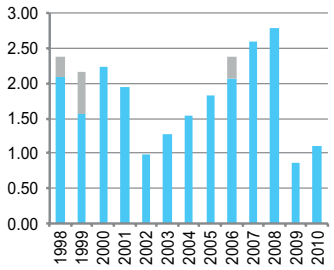
Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS

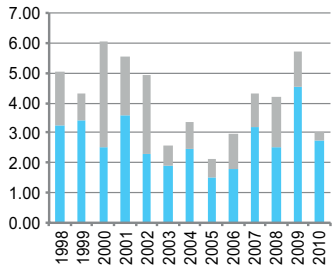
Oesophageal atresia/stenosis with or without fistula



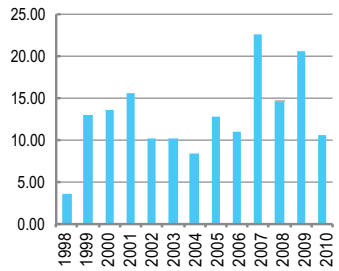
Small intestine atresia/stenosis



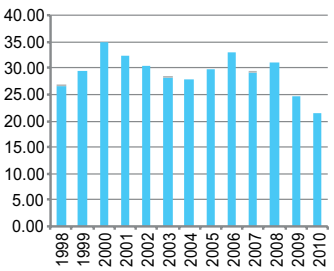
Anorectal atresia/stenosis



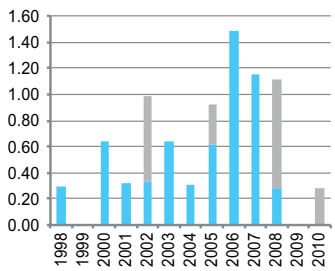
Undescended testis



Hypospadias



Indeterminate sex



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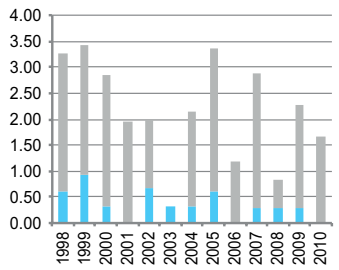
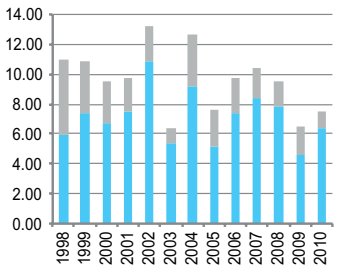
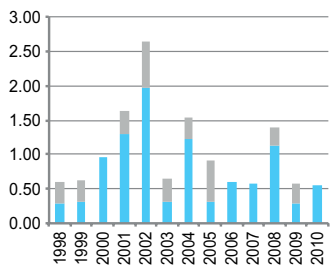


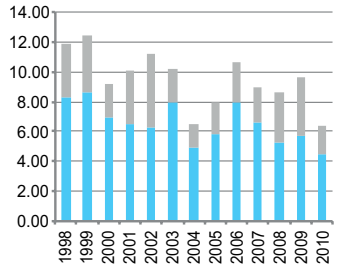
Cystic kidney



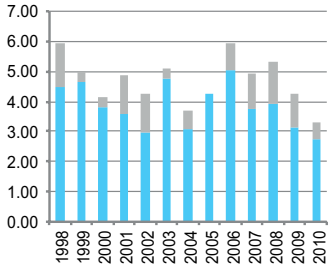
Polydactyly, preaxial



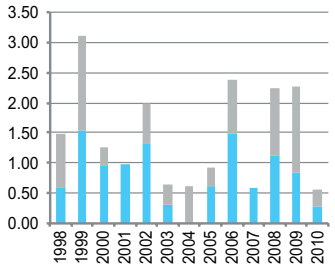
Limb reduction defects



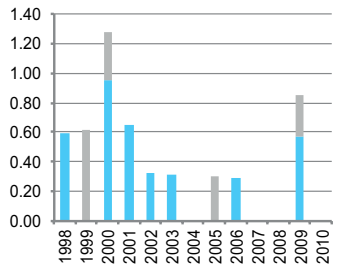
Limb reduction defects - transverse



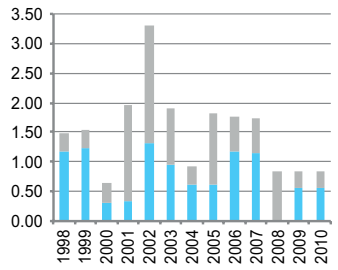
Limb reduction defects - preaxial



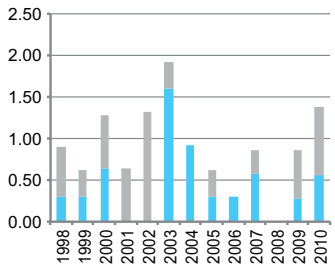
Limb reduction defects - postaxial



Limb reduction defects - intercalary

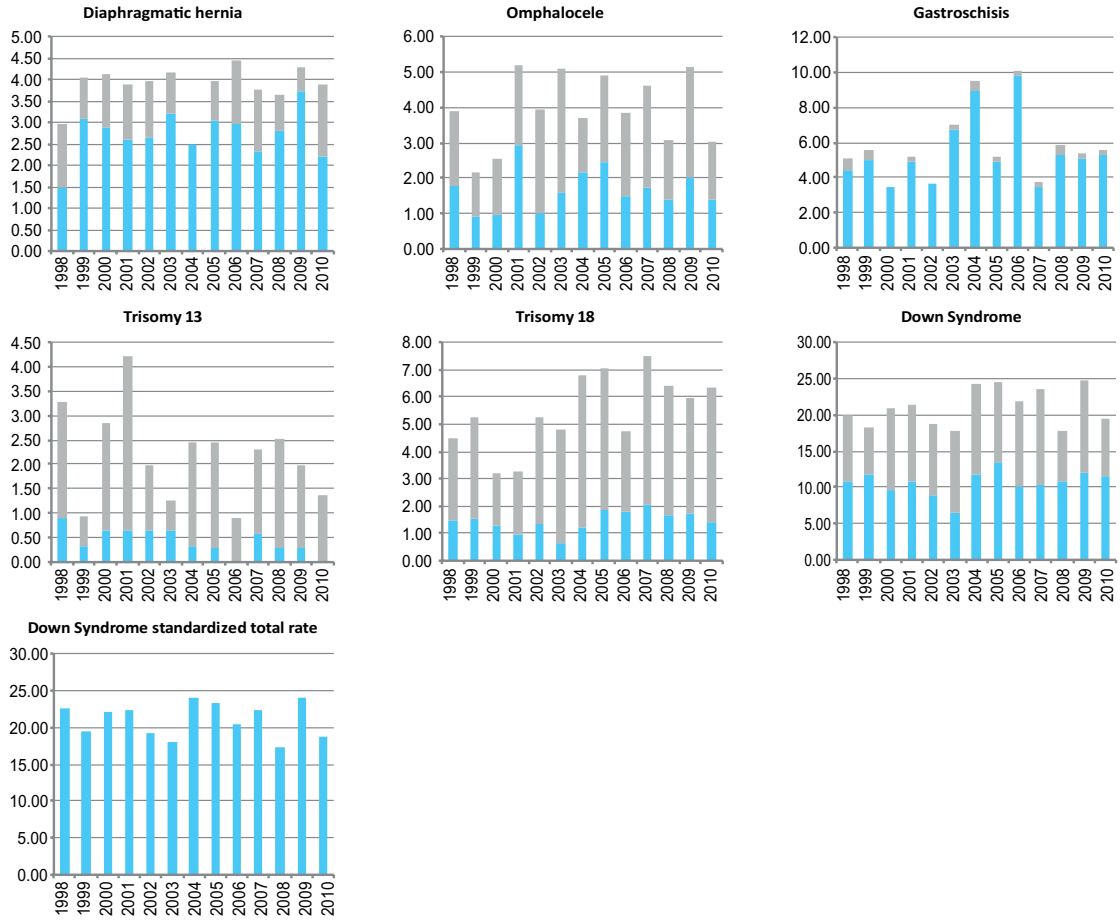


Limb reduction defects - mixed



Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS



Note: L+S rates, ToP rates

USA-Atlanta: MACDP
Metropolitan Atlanta Congenital Defects Program

History:
The Programme started in 1967 and was a founding member of the ICBDSR. The Programme is a full member of the ICBDSR. Size and coverage: The Programme covers all births within a five-county area in metropolitan Atlanta, Georgia. The annual number of births in this area is approximately 50,000. Stillbirths and terminations of at least 20 weeks gestation are included. Elective terminations at any gestational age are included.

Legislation and funding:
In 1994 the Georgia Department of Human Resources (GDHR) added birth defects to the list of legally reportable conditions in Georgia. In 1997 the GDHR authorised the Birth Defects Branch at the Centers for Disease Control and Prevention (CDC) to act with and on its behalf to collect health information on children with birth defects. The Programme is funded by the Centers for Disease Control and Prevention.

Sources of ascertainment:
Multiple sources, such as delivery units, paediatric departments, neonatal intensive care units, laboratories, prenatal diagnostic centres and tertiary care centres, are used to ascertain malformed infants born in the defined area with a follow-up to age six years.

Exposure information:
Exposure information is obtained by interview for mothers of reported malformed infants who participate in various research projects.

Background information:
Number of live births and demographic information on the five counties are obtained from vital statistics.

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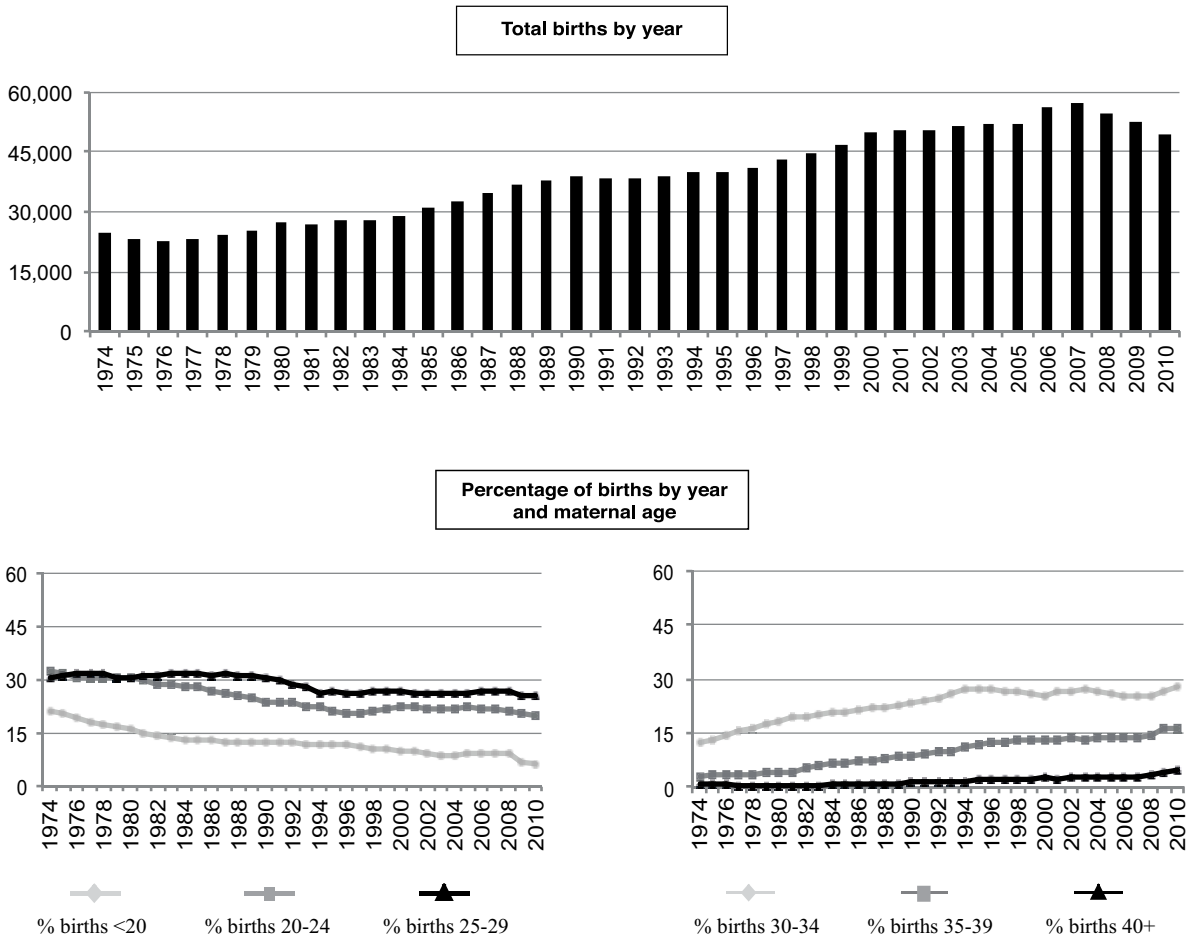
E-mail: csiffel@cdc.gov

USA-Atlanta: MACDP



Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	38	67.9	Cystic kidney (#)	14	15.4
Spina bifida	20	27.0	Limb reduction defects	12	16.2
Encephalocele	8	36.4	Diaphragmatic hernia	6	10.7
Holoprosencephaly (#)	4	20.0	Omphalocele	16	33.3
Hydrocephaly	19	11.9	Gastroschisis	7	11.7
Hypoplastic left heart syndrome	6	17.1	Trisomy 13	18	58.1
Cleft palate without cleft lip	4	4.7	Trisomy 18	46	51.7
Cleft lip with or without cleft palate	18	12.2	Down syndrome	77	24.5
Renal agenesis	8	14.5			

Total ToPs with births defects = 120 (Ratio ToPs/Births: 0.77 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)
(#) Information not available for 2010

USA-Atlanta: MACDP, 2010 (*)

Live births (LB)	48,994
Stillbirths (SB)	436
Total births	49,430
Number of terminations of pregnancy (ToP) for birth defects	120

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	0	8	2.43
Spina bifida	16	2	8	5.26
Encephalocele	5	0	2	1.42
Microcephaly	38	2	1	8.29
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	48	2	11	12.34
Anophthalmos	0	0	0	0.00
Microphthalmos	4	0	0	0.81
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.20
Microtia	6	0	0	1.21
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	21	1	0	4.45
Tetralogy of Fallot	26	1	2	5.87
Hypoplastic left heart syndrome	7	1	3	2.23
Coarctation of aorta	25	0	0	5.06
Choanal atresia. bilateral	2	0	0	0.40
Cleft palate without cleft lip	21	2	1	4.86
Cleft lip with or without cleft palate	31	1	5	7.49
Oesophageal atresia/stenosis with or without fistula	14	1	0	3.03
Small intestine atresia/stenosis	nr	nr	nr	nr
Anorectal atresia/stenosis	nr	nr	nr	nr
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	nr	nr	nr	nr
Epispadias	3	0	0	0.61
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	34	0	4	7.69
Cystic kidney	nr	nr	nr	nr
Bladder exstrophy	nr	nr	nr	nr
Polydactyly. preaxial	nr	nr	nr	nr
Total Limb reduction defects (include unspecified)	14	0	4	3.64
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	16	1	1	3.64
Omphalocele	9	2	7	3.64
Gastroschisis	10	2	2	2.83
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	5	1	4	2.02
Trisomy 18	11	3	18	6.47
Down syndrome. all ages (include age unknown)	89	5	39	26.91
<20	4	0	0	12.82
20-24	4	0	0	4.10
25-29	11	2	3	12.84
30-34	22	1	4	19.71
35-39	25	1	21	58.26
40-44	15	2	9	120.20
45+	3	0	1	250.00
unknown	5	0	1	---

(*) preliminary data
nr = not reported

USA-Atlanta: MACDP, previous years rates 1974-2010

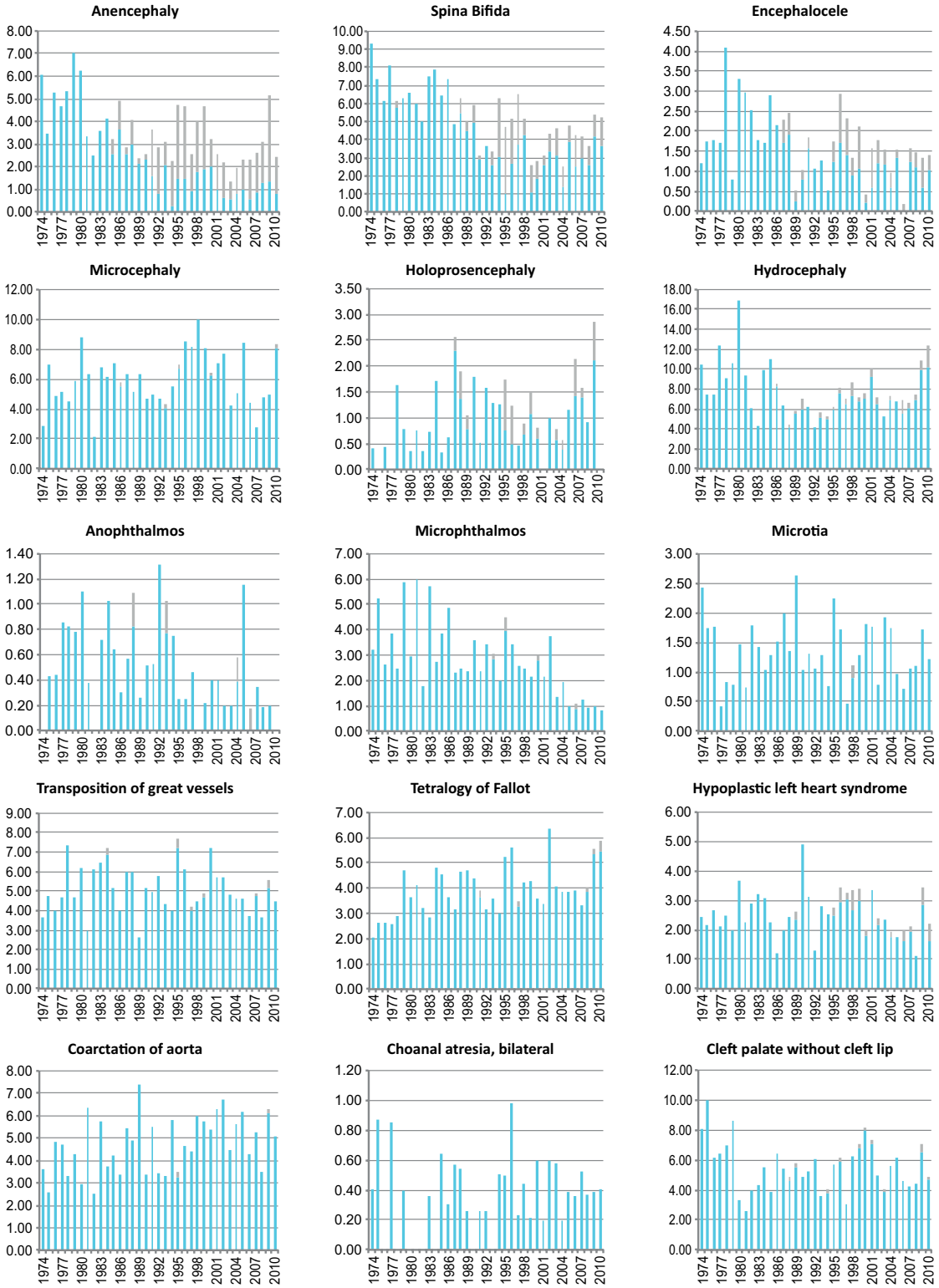
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010
Total births	**171,284**	**142,873**	**181,304**	**195,642**	**225,770**	**256,833**	**270,038**
Anencephaly	5.49	3.36	3.31	3.32	3.81	2.06	3.11
Spina bifida	7.12	6.58	5.85	4.24	4.34	3.89	4.52
Encephalocele	2.10	2.38	1.65	1.28	1.77	1.48	1.19
Microcephaly	5.60	5.74	5.63	5.32	8.19	6.50	4.96
Holoprosencephaly	0.53	0.77	1.60	1.28	0.97	0.70	1.86*
Hydrocephaly	10.74	8.19	6.34	5.52	7.71	7.28	8.74
Anophthalmos	0.64	0.56	0.55	0.77	0.27	0.51	0.19
Microphthalmos	3.74	3.99	3.09	3.07	2.70	2.02	1.00
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00*
Anotia	0.18	0.21	0.17	0.15	0.18	0.27	0.19
Microtia	1.34	1.26	1.71	1.33	1.28	1.44	1.15
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00*
Transposition of great vessels	5.08	5.60	4.74	5.37	5.40	5.10	4.44
Tetralogy of Fallot	3.04	3.92	4.14	3.78	4.21	4.28	4.48
Hypoplastic left heart syndrome	2.51	2.73	2.70	2.50	3.06	2.34	2.15
Coarctation of aorta	3.74	4.48	4.91	4.29	5.27	5.84	4.85
Choanal atresia. bilateral	0.35	0.21	0.33	0.31	0.49	0.39	0.41
Cleft palate without cleft lip	7.01	4.06	5.46	4.91	6.20	5.61	5.00
Cleft lip with or without cleft palate	11.56	11.13	9.49	9.05	9.08	8.88	9.33
Oesophageal atresia/stenosis with or without fistula	2.34	2.80	2.04	2.35	1.99	2.10	2.18
Small intestine atresia/stenosis	1.69	1.40	1.82	1.64	1.95	1.79	2.36*
Anorectal atresia/stenosis	4.55	3.78	4.08	3.48	3.63	3.08	3.67*
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	15.36*	16.35	9.47*
Hypospadias	1.11	2.17	4.91	4.80	8.95	7.63	5.57*
Epispadias	0.99	0.91	0.55	0.61	0.35	0.47	0.48
Indeterminate sex	2.39	1.26	1.38	1.18	1.33	1.64	1.50*
Renal agenesis	2.10	1.82	1.16	1.33	1.11	0.97	2.52
Cystic kidney	2.34	3.43	4.14	5.21	5.94	6.19	6.89*
Bladder exstrophy	0.53	0.14	0.22	0.31	0.09	0.12	0.18*
Polydactyly. preaxial	1.93	1.68	3.31	2.96	2.35	2.41	2.22*
'Total Limb reduction defects (include unspecified)	6.01	4.20	4.41	5.93	6.42	4.32	4.74
Transverse	3.68	3.01	2.65	3.99	3.28	2.45	2.76*
Preaxial	1.11	0.49	0.72	1.02	1.33	0.78	0.63*
Postaxial	0.23	0.14	0.33	0.36	0.27	0.27	0.18*
Intercalary	0.53	0.21	0.33	0.10	0.31	0.19	0.41*
Mixed	0.12	0.28	0.28	0.26	0.97	0.47	0.72*
Unspecified	0.35	0.07	0.11	0.20	0.27	0.12	0.23*
Diaphragmatic hernia	2.57	1.96	3.09	2.10	2.44	3.00	2.96
Omphalocele	3.85	3.29	2.70	2.66	2.70	1.71	2.70
Gastroschisis	1.63	1.89	2.59	2.56	2.26	2.84	4.37
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.06	0.00	0.00	0.00	0.00*
Prune belly sequence	0.76	0.28	0.61	0.20	0.31	0.51	0.45*
Trisomy 13	1.23	1.12	1.65	1.33	1.90	1.87	1.63
Trisomy 18	0.70	2.17	1.93	2.61	4.65	4.52	4.96
Down syndrome. all ages (include age unknown)	9.28	10.64	10.59	14.01	17.36	17.95	18.03
<20	11.25*	5.65	7.98	6.88	8.64	6.48	10.35
20-24	8.44*	6.64	7.90	7.96	9.01	6.00	7.21
25-29	9.54*	8.02	6.93	7.92	7.17	7.33	9.18
30-34	13.97*	15.97	12.56	11.85	15.02	14.47	14.68
35-39	36.73*	19.46	23.00	36.64	42.49	50.09	37.80
40-44	0.00	99.88	55.93	89.92	124.78	130.56	93.10
45+	0.00	0.00	0.00	425.53	301.72	56.18	154.56
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 or 7 years

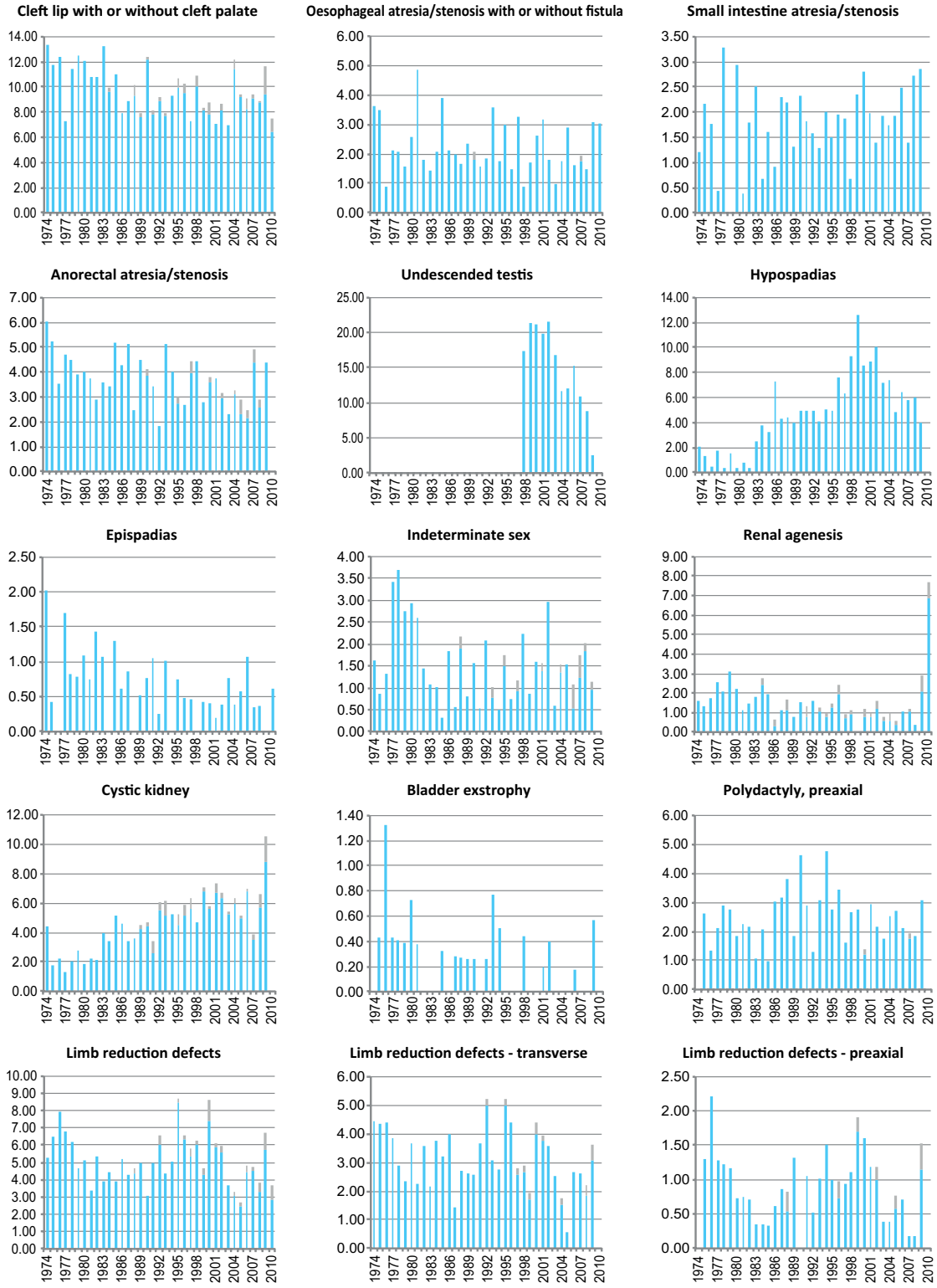
USA-Atlanta: MACDP

Time trends 1974-2010 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

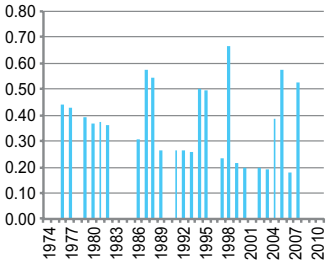
USA-Atlanta: MACDP



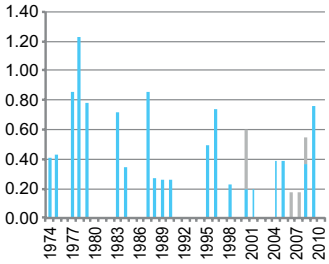
Note: L+S rates, ToP rates

USA-Atlanta: MACDP

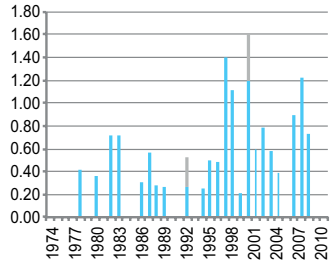
Limb reduction defects - postaxial



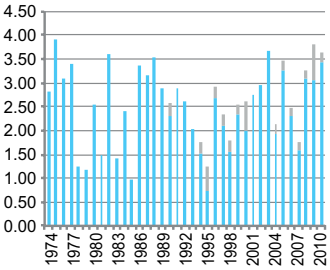
Limb reduction defects - intercalary



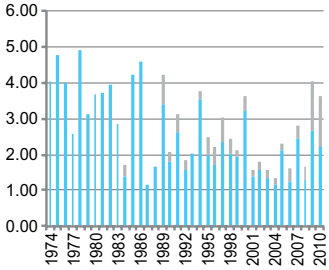
Limb reduction defects - mixed



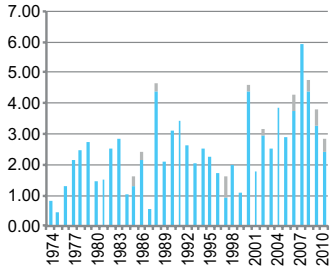
Diaphragmatic hernia



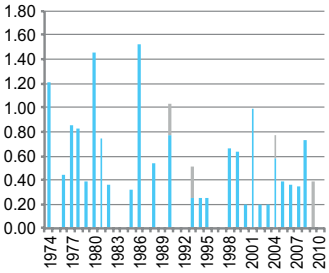
Omphalocele



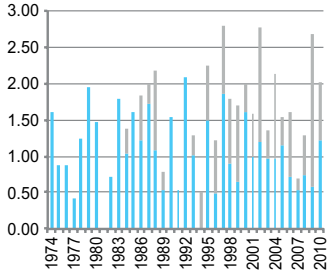
Gastroschisis



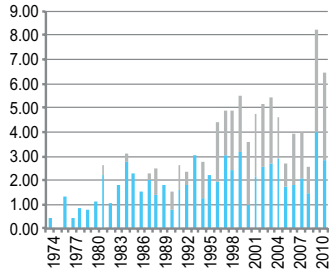
Prune belly sequence



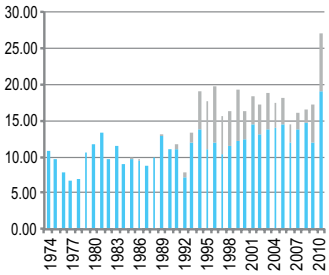
Trisomy 13



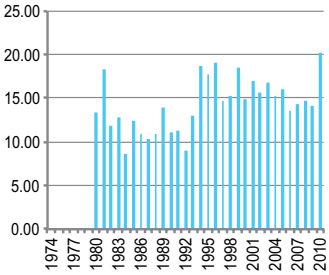
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

USA-Texas: BDES

Texas Birth Defects Epidemiology and Surveillance Branch

History:
BDES was established after an unusual cluster of anencephaly cases that occurred in Brownsville, Texas in 1991. Epidemiologic investigations revealed a higher than expected rate of neural tube defects among children born to Hispanic mothers living in South Texas. In recognition that epidemiologic resources are routinely needed to investigate birth defects clusters, the Texas State Legislature passed the Texas Birth Defects Act in 1993, which authorized the establishment of BDES. Since 1994, BDES has maintained the Texas Birth Defects Registry, an active population-based birth defects surveillance system, which has been statewide since 1999. Through multiple sources of information, the Registry monitors all births in Texas and identifies cases of birth defects. Children identified through the Registry are referred to appropriate medical and community services. In 1996, the CDC-funded Texas Center for Birth Defects Research and Prevention was established under the auspices of BDES . The Programme is a full member of the ICBDSR.

Size and coverage:
The Programme covers all deliveries to mothers residing in Texas (approximately 380,000 annually). Stillbirths and terminations of any gestational age are included. Cases diagnosed up to age one are included (up to any age for fetal alcohol syndrome). As of 2006, there were over 100,000 birth defect cases in the Registry.

Legislation and funding:
Birth defects surveillance was mandated by the Texas Birth Defects Act in 1993, and is codified in the Texas Health and Safety Code Chapter 87. About one-half of funding for the birth defects registry is from state general revenue with the remainder from federal block grants.

Sources of ascertainment:
Birth hospitals, birthing centres, lay midwives, hospitals where affected children are treated.

Exposure information:
Limited information on maternal illnesses and conditions, limited information on maternal exposures such as medications.

Background information:
Basic demographics, reproductive history, gestational age, delivery information.

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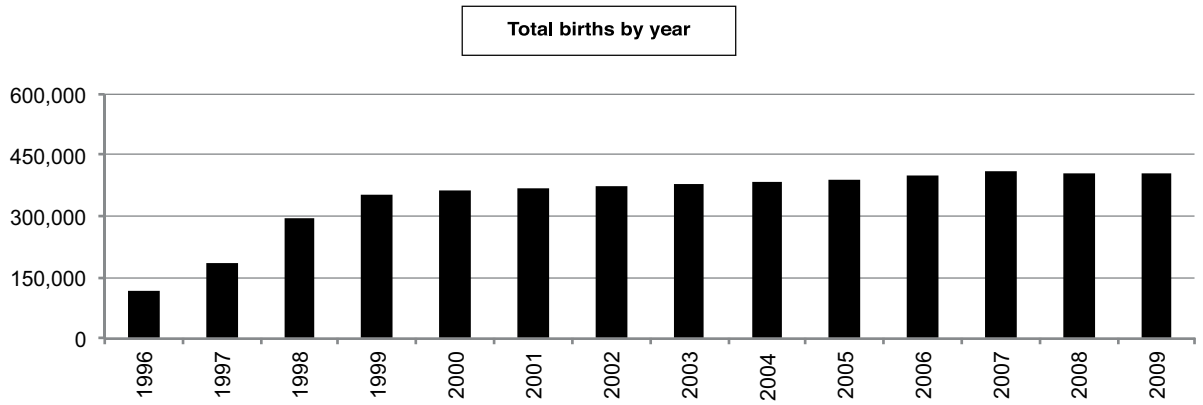
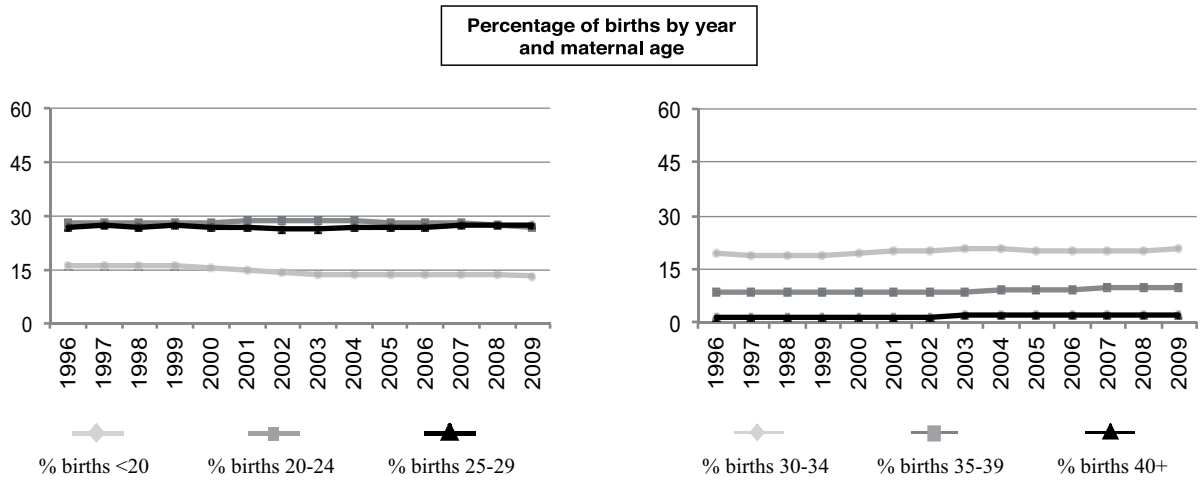
USA-Texas: BDES





Terminations of Pregnancy (ToPs) in selected malformations (2007-2009)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	104	31.9	Cystic kidney	16	2.2
Spina bifida	20	4.5	Limb reduction defects	22	3.2
Encephalocele	18	15.0	Diaphragmatic hernia	3	0.8
Holoprosencephaly	9	6.8	Omphalocele	16	6.5
Hydrocephaly	13	1.6	Gastroschisis	11	1.5
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	24	16.1
Cleft palate without cleft lip	7	1.0	Trisomy 18	63	18.8
Cleft lip with or without cleft palate	36	2.9	Down syndrome	58	3.5
Renal agenesis	21	8.6			

Total ToPs with births defects = 579 (Ratio ToPs/Births: 0.47 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Texas: BDES, 2009 (updated)

Live births (LB)	401,599
Stillbirths (SB)	2,270
Total births	403,869
Number of terminations of pregnancy (ToP) for birth defects	209

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	42	40	42	3.07
Spina bifida	137	5	9	3.74
Encephalocele	25	6	7	0.94
Microcephaly	534	3	2	13.35
Holoprosencephaly	27	3	4	0.84
Hydrocephaly	261	10	3	6.78
Anophthalmos	12	1	0	0.32
Microphthalmos	99	2	0	2.50
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	1	1	0.12
Microtia	129	0	0	3.19
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	221	0	0	5.47
Tetralogy of Fallot	148	1	0	3.69
Hypoplastic left heart syndrome	85	0	0	2.10
Coarctation of aorta	200	0	0	4.95
Choanal atresia, bilateral	54	1	0	1.36
Cleft palate without cleft lip	218	6	2	5.60
Cleft lip with or without cleft palate	343	19	10	9.21
Oesophageal atresia/stenosis with or without fistula	89	0	0	2.20
Small intestine atresia/stenosis	72	0	0	1.78
Anorectal atresia/stenosis	188	7	5	4.95
Undescended testis (36 weeks of gestation or later) ($)	501	1	0	12.43
Hypospadias	683	0	0	16.91
Epispadias	38	0	0	0.94
Indeterminate sex	10	17	5	0.79
Renal agenesis	66	3	9	1.93
Cystic kidney	262	4	5	6.71
Bladder exstrophy	5	0	0	0.12
Polydactyly, preaxial	165	2	0	4.14
Total Limb reduction defects (include unspecified)	207	10	5	5.50
Transverse	107	5	5	2.90
Preaxial	48	1	0	1.21
Postaxial	6	0	0	0.15
Intercalary	5	1	0	0.15
Mixed	30	2	0	0.79
Unspecified	11	1	0	0.30
Diaphragmatic hernia	105	3	1	2.70
Omphalocele	64	20	5	2.20
Gastroschisis	225	13	4	5.99
Unspecified Omphalocele/Gastroschisis	14	4	6	0.59
Prune belly sequence	5	0	1	0.15
Trisomy 13	32	12	9	1.31
Trisomy 18	60	30	25	2.85
Down syndrome, all ages (include age unknown)	516	12	22	13.62
<20	42	0	0	7.85
20-24	56	1	0	5.28
25-29	85	1	5	8.21
30-34	92	3	2	11.71
35-39	126	5	10	35.49
40-44	103	1	5	132.19
45+	12	1	0	256.92
unknown	0	0	0	---

(*) Only definite diagnosed cases are reported.
(§) Undescended testes is not coded in infants less than 36 weeks gestation unless another reportable defect is present or there was a medical/surgical intervention for this problem. Only 4.5% are <36 weeks gestation.

USA-Texas: BDES, Previous years rates 1996 - 2009

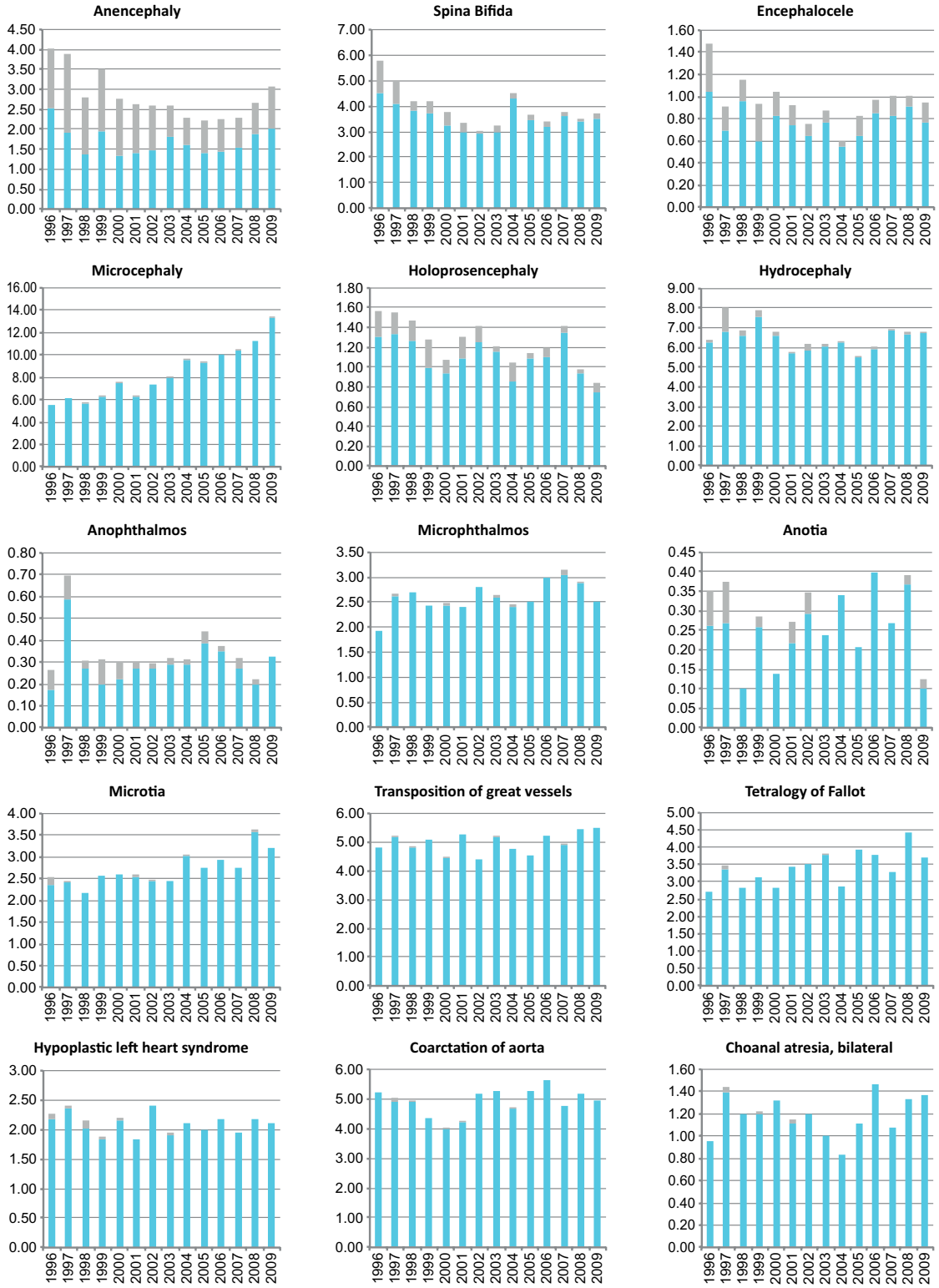
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births					**947,252**	**1,870,900**	**2,010,927**
Anencephaly					3.42	2.57	2.50
Spina bifida					4.54	3.58	3.61
Encephalocele					1.07	0.83	0.95
Microcephaly					6.01	7.73	10.90
Holoprosencephaly					1.43	1.21	1.11
Hydrocephaly					7.41	6.25	6.43
Anophthalmos					0.38	0.30	0.33
Microphthalmos					2.49	2.55	2.81
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00
Anotia					0.25	0.27	0.28
Microtia					2.42	2.64	3.05
Unspecified Anotia/Microtia					0.00	0.00	0.00
Transposition of great vessels					4.99	4.81	5.12
Tetralogy of Fallot					3.05	3.29	3.82
Hypoplastic left heart syndrome					2.11	2.10	2.08
Coarctation of aorta					4.76	4.68	5.15
Choanal atresia, bilateral					1.22	1.10	1.27
Cleft palate without cleft lip					5.81	5.37	5.74
Cleft lip with or without cleft palate					10.83	10.70	10.44
Oesophageal atresia/stenosis with or without fistula					2.24	1.99	2.06
Small intestine atresia/stenosis					1.71	1.72	1.90
Anorectal atresia/stenosis					4.44	4.85	4.94
Undescended testis (36 weeks of gestation or later)					7.83	9.19	12.27
Hypospadias					18.25	16.57	15.86
Epispadias					0.58	0.70	0.88
Indeterminate sex					1.68	1.00	0.74
Renal agenesis					2.14	1.96	1.94
Cystic kidney					4.32	4.75	5.76
Bladder exstrophy					0.18	0.26	0.14
Polydactyly, preaxial					2.82	3.27	3.84
Total Limb reduction defects (include unspecified)					5.50	5.30	5.55
Transverse					2.59	2.71	2.88
Preaxial					1.14	1.07	1.24
Postaxial					0.26	0.21	0.24
Intercalary					0.10	0.12	0.18
Mixed					1.25	0.95	0.82
Unspecified					0.17	0.23	0.18
Diaphragmatic hernia					2.70	2.63	2.84
Omphalocele					2.29	2.14	2.02
Gastroschisis					3.77	4.16	5.77
Unspecified Omphalocele/Gastroschisis					0.62	0.64	0.55
Prune belly sequence					0.26	0.31	0.26
Trisomy 13					1.18	1.20	1.12
Trisomy 18					2.46	2.23	2.69
Down syndrome, all ages (include age unknown)					11.93	12.80	13.36
<20					7.63	7.08	7.61
20-24					6.87	6.53	6.66
25-29					6.44	7.48	7.42
30-34					12.30	12.11	13.24
35-39					35.50	36.57	35.86
40-44					108.22	121.40	113.07
45+					116.86	195.84	192.06
unknown					---	---	---

* data include less than 5 years

USA-Texas: BDES

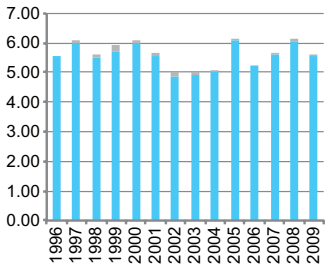
Time trends 1996-2009 (Birth prevalence rates per 10,000)



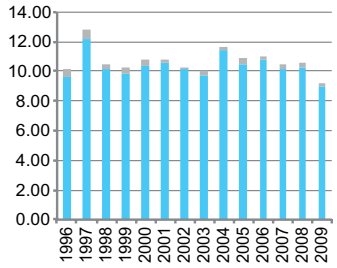
Note: L+S rates, ToP rates

USA-Texas: BDES

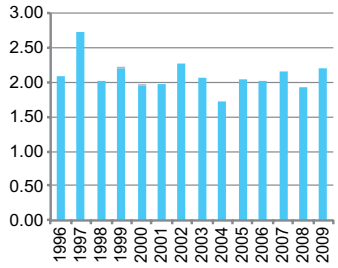
Cleft palate without cleft lip



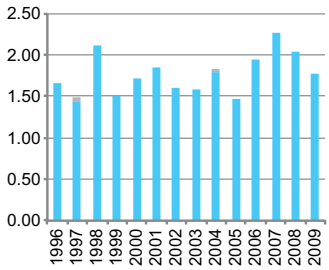
Cleft lip with or without cleft palate



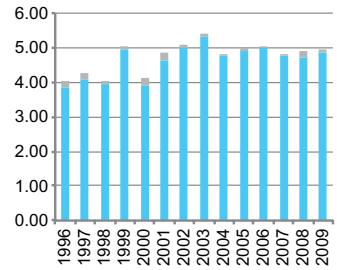
Oesophageal atresia/stenosis with or without fistula



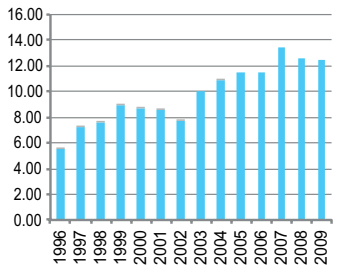
Small intestine atresia/stenosis



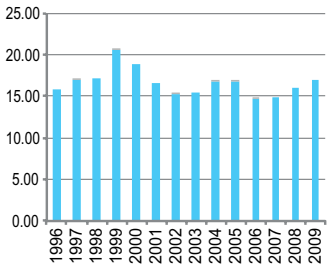
Anorectal atresia/stenosis



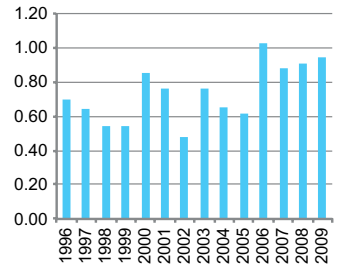
Undescended testis



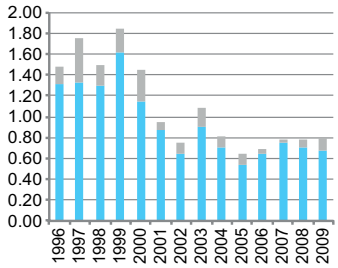
Hypospadias



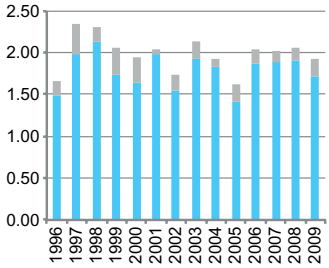
Epispadias



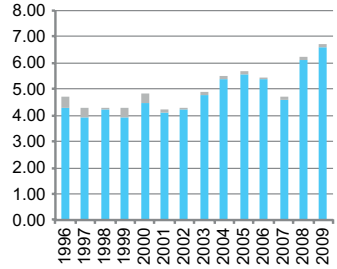
Indeterminate sex



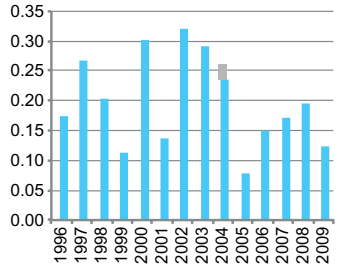
Renal agenesis



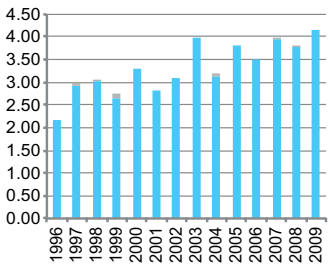
Cystic kidney



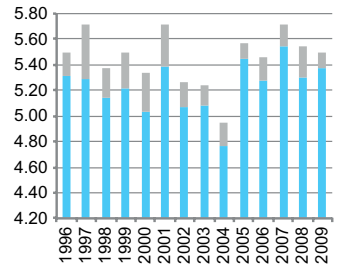
Bladder exstrophy



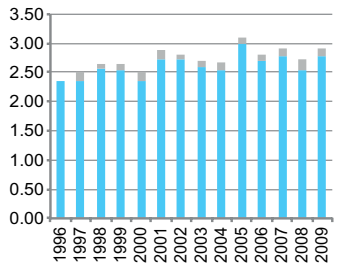
Polydactyly, preaxial



Limb reduction defects



Limb reduction defects - transverse



Note: L+S rates, ToP rates

USA-Texas: BDES

Note: L+S rates, ToP rates

USA-Utah: UBDN
Utah Birth Defects Network

History:
The Utah Birth Defect Network (UBDN) began in 1994 monitoring neural tube defects, expanding its identification of major malformations through 1999 when all major structural birth defects were identified. The program is a full member of the ICBDSR.

Size and coverage:
The UBDN is a statewide population-based surveillance system covering over 50,000 births annually.

Legislation and funding:
In 1999 an Administrative Rule was enacted under the Utah Health Code Statute which mandates all delivery hospitals and laboratories to report any pregnancy or infant diagnosed with a birth defect. This administrative rule also covers those health care providers and other agencies that voluntarily report a birth defect case to the UBDN. The UBDN surveillance staff is funded by both state and federal funds. The UBDN has many research projects funded from federal sources (e.g., Centers for Disease Control and Prevention).

Sources of ascertainment:
Multiple sources (n=128), such as delivery units, paediatric departments, laboratories, prenatal diagnostic centers, hospital discharge data, other specialties, and champions are used to ascertained malformed infants born in Utah. These sources include reports that are generated by the facilities, case reports submitted by individual care providers, as well as reports actively obtained by UBDN staff reviewing records or log books.

Exposure information:
Basic risk factors including medications taken during pregnancy, infections, chronic conditions are all recorded based on medical records abstraction.

Background information:
Detailed background information including demographics, reproductive history, gestational age, prenatal diagnostics, and family history are all collected from the medical record. The number of births and basic demographic data are obtained from vital statistics.

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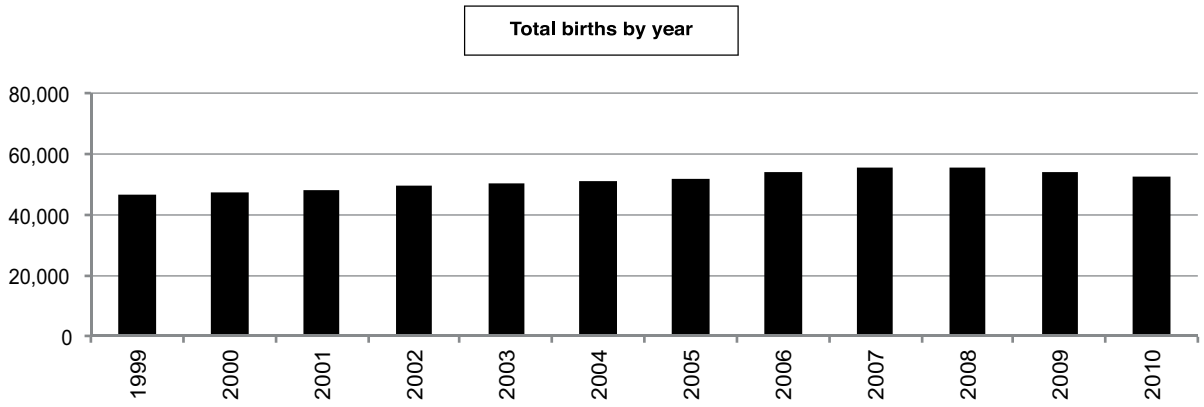
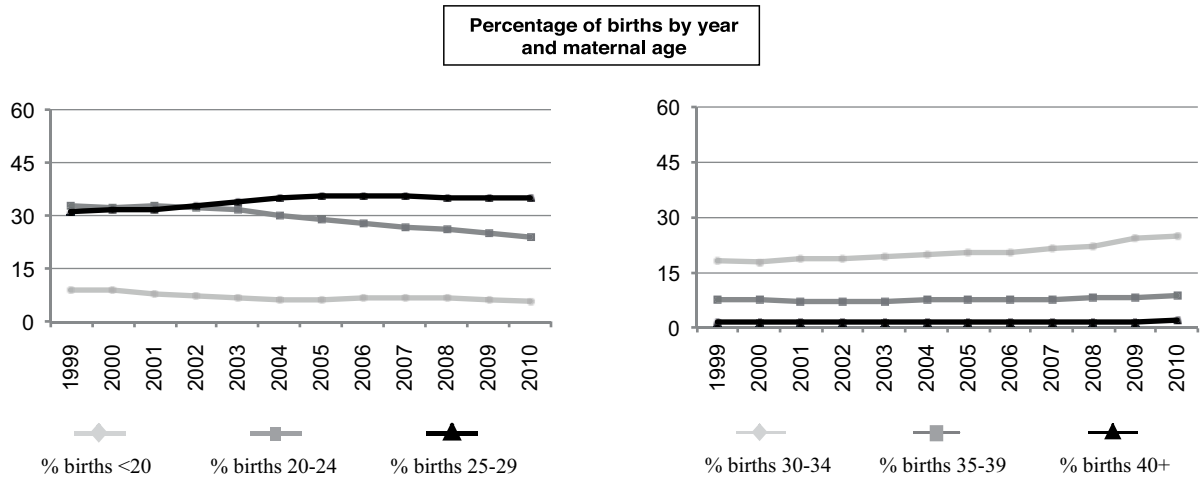
USA-Utah: UBDN





Terminations of Pregnancy (ToPs) in selected malformations (2008-2010)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	23	50.0	Cystic kidney	9	12.3
Spina bifida	7	13.0	Limb reduction defects	7	6.9
Encephalocele	5	31.3	Diaphragmatic hernia	2	3.6
Holoprosencephaly	8	25.0	Omphalocele	10	17.2
Hydrocephaly	2	6.9	Gastroschisis	1	1.2
Hypoplastic left heart syndrome	1	1.8	Trisomy 13	8	28.6
Cleft palate without cleft lip	1	1.2	Trisomy 18	15	27.3
Cleft lip with or without cleft palate	12	5.3	Down syndrome	27	11.8
Renal agenesis	4	9.1			

Total ToPs with births defects = 137 (Ratio ToPs/Births: 0.84 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Utah: UBDN, 2010

Live births (LB)	52,164
Stillbirths (SB)	295
Total births	52,459
Number of terminations of pregnancy (ToP) for birth defects	32

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	4	9	2.86
Spina bifida	8	0	4	2.29
Encephalocele	4	0	0	0.76
Microcephaly	7	0	0	1.33
Holoprosencephaly	0	3	1	0.76
Hydrocephaly	5	0	0	0.95
Anophthalmos	3	0	0	0.57
Microphthalmos	3	0	0	0.57
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.19
Microtia	15	0	0	2.86
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	0	1.33
Tetralogy of Fallot	18	0	0	3.43
Hypoplastic left heart syndrome	13	2	0	2.86
Coarctation of aorta	44	1	3	9.15
Choanal atresia, bilateral	10	0	1	2.10
Cleft palate without cleft lip	22	1	0	4.38
Cleft lip with or without cleft palate	65	5	4	14.11
Oesophageal atresia/stenosis with or without fistula	13	0	0	2.48
Small intestine atresia/stenosis	8	0	0	1.53
Anorectal atresia/stenosis	11	0	3	2.67
Undescended testis (36 weeks of gestation or later)	0	0	0	0.00
Hypospadias	50	0	0	9.53
Epispadias	1	0	0	0.19
Indeterminate sex	0	0	0	0.00
Renal agenesis	13	2	2	3.24
Cystic kidney	25	1	2	5.34
Bladder exstrophy	3	0	0	0.57
Polydactyly, preaxial	0	0	0	0.00
Total Limb reduction defects (include unspecified)	24	3	2	5.53
Transverse	15	1	0	3.05
Preaxial	5	0	1	1.14
Postaxial	3	0	0	0.57
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	2	0	0	0.38
Diaphragmatic hernia	12	1	1	2.67
Omphalocele	11	3	3	3.24
Gastroschisis	23	0	0	4.38
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	2	0.57
Trisomy 13	4	0	3	1.33
Trisomy 18	10	6	1	3.24
Down syndrome, all ages (include age unknown)	58	2	6	12.58
<20	2	0	0	6.52
20-24	9	0	0	7.21
25-29	10	1	0	6.05
30-34	18	0	1	14.66
35-39	7	1	2	21.92
40-44	11	0	3	165.68
45+	1	0	0	166.67
unknown	58	2	6	---

USA-Utah: UBDN, Previous years rates 1999 - 2010

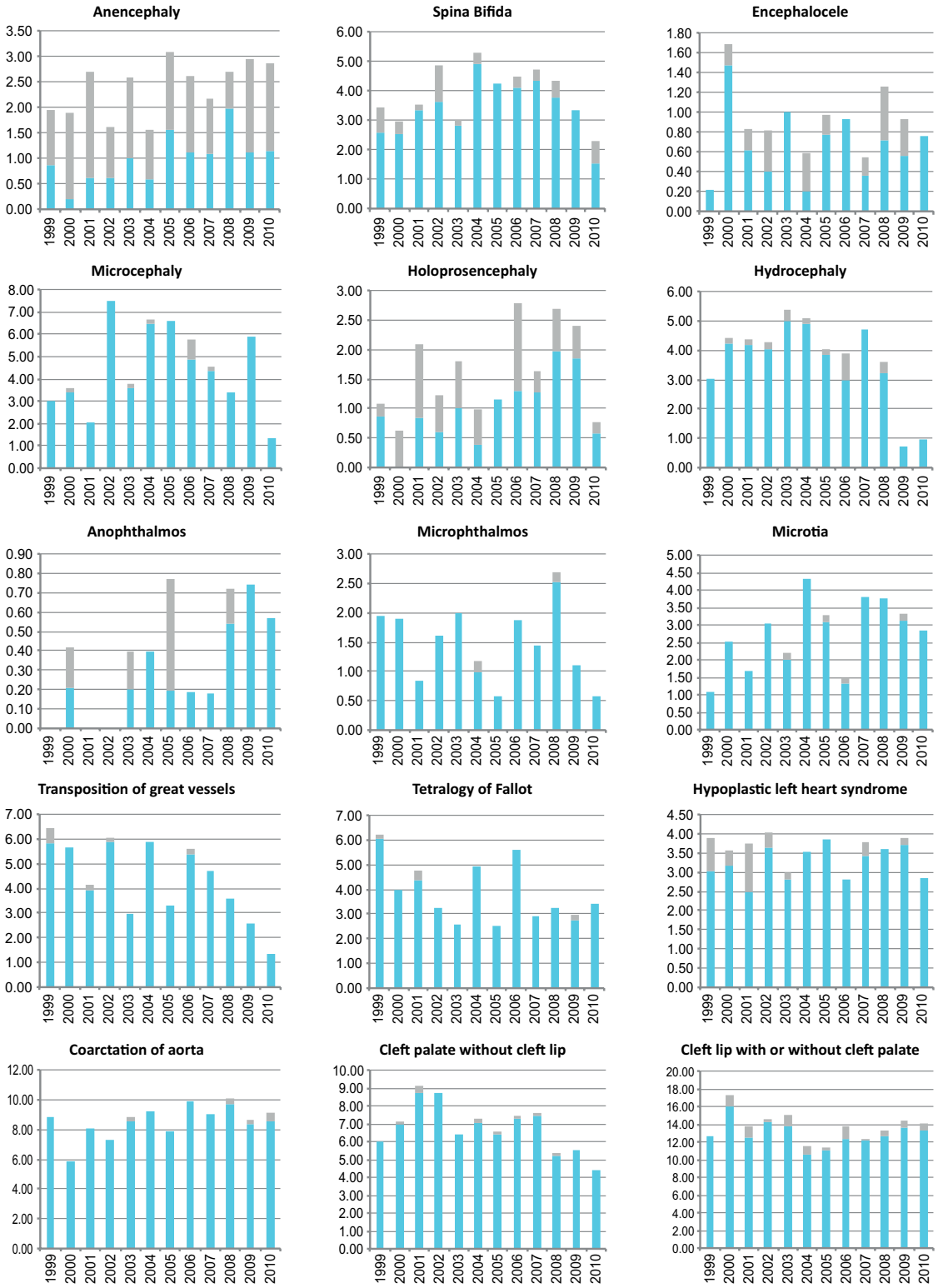
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1980	1981-1985	1986-1990	1991-1995	1996-2000*	2001-2005	2006-2010
Total births					**94,036**	**250,310**	**271,250**
Anencephaly					1.91	2.32	2.65
Spina bifida					3.19	4.19	3.83
Encephalocele					0.96	0.84	0.88
Microcephaly					3.30	5.35	4.20
Holoprosencephaly					0.85	1.44	2.06
Hydrocephaly					3.72	4.63	2.80
Anophthalmos					0.21	0.32	0.48
Microphthalmos					1.91	1.24	1.55
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00
Anotia					0.21	0.12	0.11
Microtia					1.81	2.92	3.06
Unspecified Anotia/Microtia					0.00	0.00	0.00
Transposition of great vessels					6.06	4.47	3.58
Tetralogy of Fallot					5.10	3.60	3.61
Hypoplastic left heart syndrome					3.72	3.64	3.39
Coarctation of aorta					7.34	8.27	9.36
Choanal atresia, bilateral					0.00	0.28	0.74
Cleft palate without cleft lip					6.59	7.59	6.08
Cleft lip with or without cleft palate					14.99	13.22	13.57
Oesophageal atresia/stenosis with or without fistula					2.76	2.56	2.84
Small intestine atresia/stenosis					1.28	1.36	1.44
Anorectal atresia/stenosis					3.19	3.56	3.24
Undescended testis (36 weeks of gestation or later)					nr	nr	0.00*
Hypospadias					4.36	5.59	9.73
Epispadias					0.32	0.16	0.07
Indeterminate sex					nr	nr	0.00*
Renal agenesis					3.30	3.72	3.13
Cystic kidney					4.68	5.71	4.46
Bladder exstrophy					0.32	0.16	0.22
Polydactyly, preaxial					nr	nr	0.00*
Total Limb reduction defects (include unspecified)					5.74	6.55	6.01
Transverse					3.40	3.16	3.13
Preaxial					1.38	1.64	1.36
Postaxial					0.11	0.12	0.29
Intercalary					0.00	0.16	0.26
Mixed					0.53	1.04	0.70
Unspecified					0.21	0.16	0.29
Diaphragmatic hernia					3.30	3.52	3.21
Omphalocele					2.76	2.44	3.17
Gastroschisis					3.72	5.27	5.01
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00
Prune belly sequence					0.00	0.20	0.37
Trisomy 13					1.17	1.68	2.06
Trisomy 18					3.72	3.24	3.50
Down syndrome, all ages (include age unknown)					14.78	15.66	14.08
<20					10.57	10.32	7.96
20-24					7.49	8.76	7.67
25-29					9.13	9.00	7.44
30-34					10.66	15.26	13.23
35-39					60.60	47.00	40.82
40-44					128.40	158.13	167.26
45+					217.39	531.40	252.71
unknown					---	---	---

nr = not reported
* data include less than 5 years

USA-Utah: UBDN

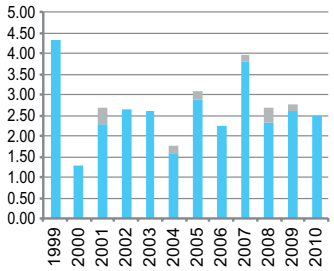
Time trends 1999-2010 (Birth prevalence rates per 10,000)



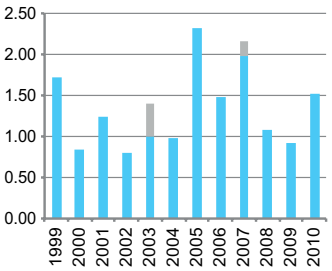
Note: L+S rates, ToP rates

USA-Utah: UBDN

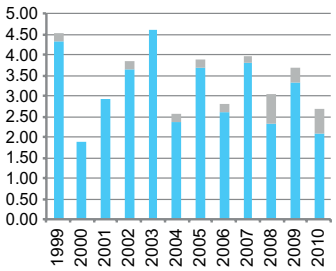
Oesophageal atresia/stenosis with or without fistula



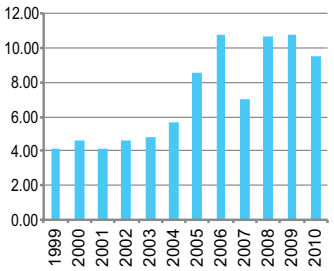
Small intestine atresia/stenosis



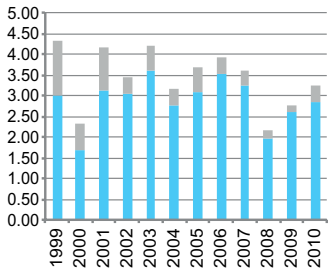
Anorectal atresia/stenosis



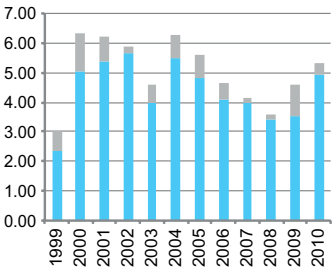
Hypospadias



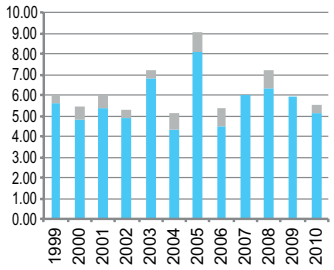
Renal agenesis



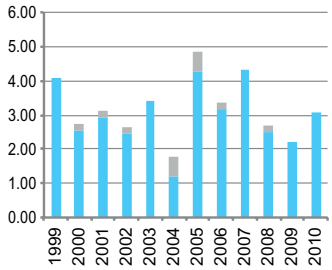
Cystic kidney



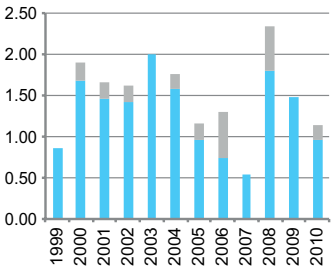
Limb reduction defects



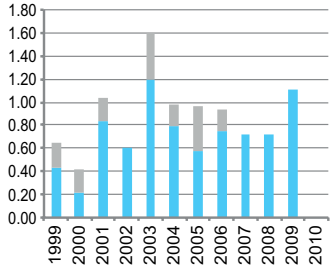
Limb reduction defects - transverse



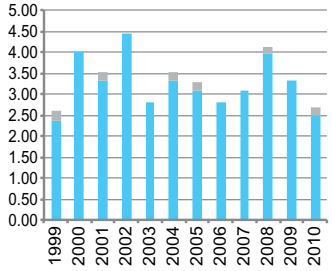
Limb reduction defects - preaxial



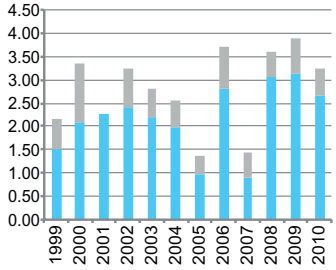
Limb reduction defects - mixed



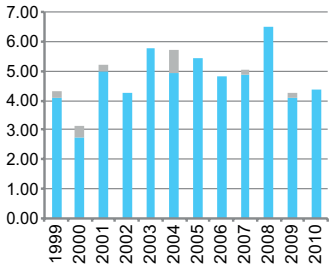
Diaphragmatic hernia



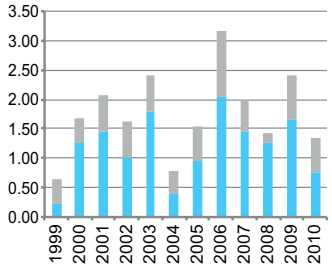
Omphalocele



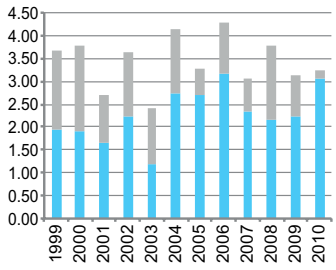
Gastroschisis



Trisomy 13

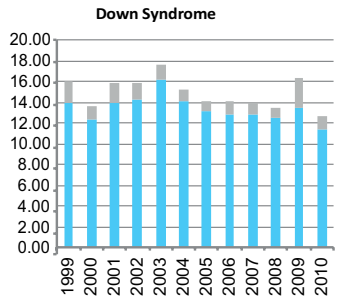


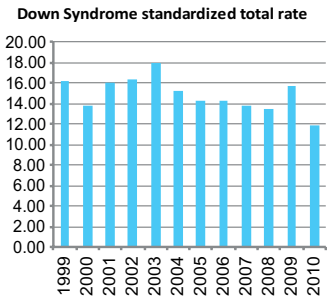
Trisomy 18



Note: L+S rates, ToP rates

USA-Utah: UBDN





Note: L+S rates, ToP rates

Monitoring Systems, not contributing with Annual Data: description of the registry

Australia: VBDR
Victorian Birth Defects Registry

History:
In 1979 the Commonwealth Government agreed in principle to collect more information about births and birth defects. It was decided that the States would be responsible for setting up their own systems and the Commonwealth would establish a National Perinatal Statistics Unit, to collate information from all the states and provide an overall picture. The Victorian Perinatal Data Collection Unit (VPDCU), established under the Health Act of 1958, operates under the aegis of the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (the Council). One of the fundamental purposes of the VPDCU was the establishment and maintenance of the Victorian Birth Defects Register (VBDR). The VPDCU and VBDR were established in 1982.

Size and coverage:
The VBDR collects information on all birth defects for livebirths, stillbirths and terminations of pregnancy pre 20 wks gestation and children up to 18 yrs of age (irrespective of the age at diagnosis). Approximately 3.8% of babies are born with a birth defect at or after 20 weeks gestation. We also follow up terminations for birth defects before 20 weeks, once these are included the overall prevalence is approximately 4%. Birth defects are notified to the register for those babies/fetus' who were born in Victoria.

Legislation and funding:
The ongoing maintenance of the VBDR is enshrined in the legislation pertaining to the VPDCU (Health Act 1958) and is an ongoing function of the VPDCU, however notification of birth defects outside the reporting period on the Perinatal Morbidity Statistics form (28 days) is a voluntary process. There is a section for reporting of birth defects on the Perinatal form which is completed at the time of birth. Several measures are taken to ensure the ascertainment of birth defects outside this reporting period which will be specified in 'sources of ascertainment'. The VPDCU & VBDR are funded by the Department of Human Services (State Government).

Sources of ascertainment:
Perinatal forms (approx 48.8%)
Hospital listings* (aPprox 28.8%)
Perinatal death certificates/autopsy reports (approx 7.8%)
Cytogenetic reports (approx 9.3%)
Maternal & Child Health Nurse (approx 4.2%)
Other professionals/parents (approx 1.1%)
* These include obtaining annual inpatient listings from the two major paediatric teaching hospitals detailing all children up to the age of five years who have been subsequently admitted to these hospitals each year with a birth defect. We also obtain annual listings from specialist clinics at these hospital for all children up to the age of five years who have visited either as an inpatient or an outpatient. This procedure has also been adopted for Monash Medical Centre. Other listings are also received from Newborn Screening Services and Genetic Health Services Victoria.

Exposure information:
No exposure information is available.

Addresses and Staff:
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Acting Manager
Clinical Councils Unit
Department of Health
50 Lonsdale Street, Melbourne, Victoria 3000, Australia
Phone 03 9096 2693
Fax 03 9096 2700
E-mail: katharine.l.gibson@health.vic.gov.au

Canada: British Columbia

British Columbia Health Status Registry (BCHSR)
Congenital Anomalies Surveillance Programme

History:
The Programme was established in 1952 as the Crippled Children's Registry. Until 1959 the Programme had an age limit of 21, but this was removed in 1960 and the name was changed to the Registry for Handicapped Children and Adults and included all familial conditions and congenital malformations. In 1975, the Registry's name was changed to the Health Surveillance Registry as risk registers for amniocentesis, rubella, hyaline membrane disease, and fetal alcohol syndrome were added. In 1991, the Royal Commission Report on Health Care and Costs contained a recommendation that Vital Statistics should develop and maintain a registry of individuals with disabilities to assist in the development of long-range plans and to monitor the changing needs of the population. Subsequently, in September 1992, amendments to the Health Act established the legislative mandate and responsibilities for the HSR. The Registry's current name, Health Status Registry, was acquired in 1992. In order to refocus the Registry's emphasis on children, the criteria for registration of individuals with long-term physical, mental and/or emotional problems was restricted to persons under the age of 20 years old, however registration of persons with genetic conditions was not age limited. By 2000 there were approximately 215,000 records in the Registry.

Size and coverage:
The registry covers all births in the province approximately 45,000 births annually including stillbirths with at least 20 weeks gestation or birth weight 500 grams or more.

Legislation and funding:
In 1992, amendments to the Health Act established the legislative mandate and responsibilities for the BC HSR. Funding comes from the British Columbia Vital Statistics Agency.

Sources of ascertainment:
Sources include: Notice of Live and Stillbirth, Death registrations, Hospital Admission/Discharge Abstracts, Children's Hospital, Sunnyhill Hospital, UBC and Victoria General Medical Genetics Clinics, Child Development Centres, Health Regions, the Asante Centre for Fetal Alcohol Syndrome.

Exposure information:
Information on complications of pregnancy, labour or delivery is available on Vital Statistics birth registrations and environmental/occupational and drug/alcohol/smoking lifestyle related information can be obtained from the death registrations for the deceased.

Background information:
The registry data are regularly matched to Vital Statistics birth registrations to obtain birth particulars of the registrants and maternal/paternal information, and also matched to death registrations to get the date of death and causes of death if the registered person was deceased. The registry also registers cases of medically terminated pregnancies due to congenital anomalies.

Addresses and Staff:
Health Sector IM/IT Division
Ministry of Health Services
7-1, 1515 Blanshard Street, Victoria,
British Columbia, CANADA, V8W 3C8

France: Strasbourg
Registry of Congenital Malformations

History:
The registry was started in 1979. The Programme became member of the Clearinghouse in 1982.

Size and coverage:
All births in an area including and around Strasbourg and the Bas-Rhin are covered -13,000 to 13,500 annually, or 1,8% of all births in France.

Legislation and funding:
The Programme is a research Programme, recognised by the local health authorities and funded by Institut National de Veille Sanitaire and INSERM.

Sources of ascertainment:
Reports are obtained from paediatricians, gynecologists, pathologists, surgeons and geneticists.

Exposure information:
Detailed information on various exposures is obtained from medical records. The children are followed to the age of two years.

Background information:
General demographic information is obtained from the National Institute of Statistics (INSEE). Further information is obtained from Social Security Records and Health Sheets.

Addresses and Staff:
Bérénice Doray, Programme Director
Service de Génétique Médicale
Hôpital de Hautepierre
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67098 Strasbourg Cedex, France
Phone: 33-3-88138120
E-mail: Berenice.Doray@chru-strasbourg.fr

Italy: North-East

North-East Italy Registry of Congenital Malformations

History:
The Registry was established in 1981 to include the Veneto, Friuli Venezia Giulia and Trentino Alto Adige regions. The Registry became a member of Eurocat in 1985, and an associate member of Clearinghouse in 1997.

Size and coverage:
Reports are obtained from 60 participating hospitals, with a total of approximately 57,000 annual births; the actual coverage is estimated at 73%.

Legislation and funding:
Reporting is voluntary. The Programme is partly run by privately funded research organisations and partly by Regional Health Authorities.

Sources of ascertainment:
Reports are obtained on specific forms from delivery units, induced abortion units, pediatric, cardiology, ophthalmology and pathology departments, regional induced abortion database and cytogenetic laboratories. 32 selected malformations are recorded within 7 days from birth (within 3 years of age for cardiovascular and ophthalmological anomalies only). In induced abortions all fetal anomalies are recorded. Two control infants are selected for each malformed one.

Exposure information:
Detailed information on various exposures, including maternal or paternal occupation, diseases and drug use is obtained by interview of the mothers at the birth of the malformed nfants and controls. Only selected malformations are colected.

Background information:
Some epidemiological background data of all births are available. For each participating hospital the number of livebirths and stillbirths by sex and number of twin pairs are known.

Addresses and Staff:
Romano Tenconi, MD, Programme Director, until May 23, 2010

Maurizio Clementi, MD, Programme Director, from May 24, 2010
Servizio di Informazione Teratologia
Genetica Clinica, Dipartimento Pediatria
Università di Padova
Via Giustiniani, 3
35128 Padova, Italy
Phone: 39-049-8213513
Fax: 39-049-8211425
E-mail: Maurizio.clementi@unipd.it

Russia – Moskow Region: MRRCM

Moscow Regional Registry of Congenital malformation

History:
Moscow Regional Registry of Congenital malformation started the activity in 1999 and legally defined by the order of the Ministry of Health Care of Russian Federation. MRRCM became a Member of ICBDSR in 2001.

Size and coverage:
MRRCM be located as a section of Moscow Regional Medical genetic consultation by The Moscow Regional Research institute of Obstetrics and Gynecology (MONIIAG). Director of the MONIIAG is Professor Vladislav Krasnopolsky. The Head of the Moscow Regional Medical genetic consultation and Director of the Programme of MRRCM is Ludmila Joutchenko. The Programme of Monitoring of Birth defects covers all births in Moscow Region. In 1999 MRRCM observed 45,000 birth. There are about 64,000 births today (2007). The information about babies and fetuses with Birth defects collect from 54 maternity hospitals also from all women consultations and clinics, children clinics. Prenatal diagnosed and terminated fetuses are register also.

Legislation and funding:
Monitoring of the birth of fetuses and babies with congenital malformations is legally defined by the Order of the Ministry of Health Care of Russian Federation in 1999.

Sources of ascertainment:
Reporting is made by neonatologist during the first week of the infant's life in maternity hospitals and by pediatricians during the first year – in pediatric clinics and departments. Reports are collected from cytogenetic laboratories, pathology departments.

Exposure information:
No exposure information is routinely collected in the registry.

Background information:
Background information on all births is available from statistics department.

Addresses and Staff:
Ludmila Joutchenko, MD, Programme Director
Moscow Regional Research Scientific Institute of Obstetrics and Gynecology
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101000 Moscow Russia
Phone: 007-0959356228
Fax: 007-0959215398
E-mail: mrrcm@mail.ru

USA: California
California Birth Defects Monitoring Program

History:
The California Birth Defects Monitoring Program was established in 1983 to monitor rates and trends and conduct epidemiological investigations to find causes of birth defects. The Program has had both state and federal funding, and is a branch of the California Department of Public Health, within the Maternal, Child and Adolescent Health Division.

Size and coverage:
The Program operates a population-based registry among approximately 223,000 births. The registry includes 12 counties whose birth defects rates and trends are representative of California which reflect the state's racial/ethnic diversity.

Legislation and funding:
The Program operates under statutory authority: Health and Safety Code Sections 103825-103855. The Program has received money from these sources in the past: Federal Block Grant Funds from Title V, State General Fund, and special funds from the Prenatal Genetic Disease Screening Program. Since July 2009, only Title V funding remains for the Registry.

Sources of ascertainment:
Staff actively ascertain data at hospitals and genetic centers by reviewing logs and identifying children with structural birth defects generally encompasses within BPA 740-759, diagnosed prenatally through age one. All diagnostic information is abstracted direct from medical records; registry files are cross-linked with vital statistics data to verify demographic information.

Background information:
Registry data, a description of Program activities, research findings, and publications are available at www.cdph.ca.gov

Contact information:
Marcia Ehinger, MD, Program Director
California Birth Defects Monitoring Program
California Department of Public Health
Maternal, Child and Adolescent Health Division
Center for Family Health
1615 Capitol Avenue, MS 8300
Sacramento, CA 95814, USA
Phone: (916) 650-0367
E-mail: Marcia.ehinger@cdph.ca.gov

Selection of papers by Programme Directors and their collaborators are reported as following. The details are sent from the Programme Directors only for the listed Surveillance Progrrams. Collaborative publications, made by two or more ICBDSR members in any context, are first shown and not repeated in the specific Surveillance System list. Papers can be requested to Authors

Collaborative Publications, 2011 - 2012

Poletta FA, López Camelo JS, Gili JA, Leoncini E, Castilla EE, Mastroiacovo P. Methodological approaches to evaluate teratogenic risk using birth defect registries: advantages and disadvantages. PLoS One. 2012;7(10):e46626

Nassar N, Leoncini E, Amar E, Arteaga-Vázquez J, Bakker MK, Bower C, Canfield MA, Castilla EE, Cocchi G, Correa A, Csáky-Szunyogh M, Feldkamp ML, Khoshnood B, Landau D, Lelong N, López-Camelo JS, Lowry RB, McDonnell R, Merlob P, Métneki J,Morgan M, Mutchinick OM, Palmer MN, Rissmann A, Siffel C, Sìpek A, Szabova E, Tucker D, Mastroiacovo P. Prevalence of esophageal atresia among 18 international birth defects surveillance programs. Birth Defects Res A Clin Mol Teratol. 2012 Sep 3. [Epub ahead of print]

Bermejo-Sánchez E, Cuevas L, Amar E, Bakker MK, Bianca S, Bianchi F, Canfield MA, Castilla EE, Clementi M, Cocchi G, Feldkamp ML, Landau D, Leoncini E, Li Z, Lowry RB, Mastroiacovo P, Mutchinick OM, Rissmann A, Ritvanen A, Scarano G, Siffel C, Szabova E, Martínez-Frías ML. Amelia: a multi-center descriptive epidemiologic study in a large dataset from the International Clearinghouse for Birth Defects Surveillance and Research, and overview of the literature. Am J Med Genet C Semin Med Genet. 2011 Nov 15;157C(4):288-304.

Bermejo-Sánchez E, Cuevas L, Amar E, Bianca S, Bianchi F, Botto LD, Canfield MA, Castilla EE, Clementi M, Cocchi G, Landau D, Leoncini E, Li Z, Lowry RB, Mastroiacovo P, Mutchinick OM, Rissmann A, Ritvanen A, Scarano G, Siffel C, Szabova E, Martínez-Frías ML. Phocomelia: a worldwide descriptive epidemiologic study in a large series of cases from the International Clearinghouse for Birth Defects Surveillance and Research, and overview of the literature. Am J Med Genet C Semin Med Genet. 2011 Nov 15;157C(4):305-20.

Botto LD, Feldkamp ML, Amar E, Carey JC, Castilla EE, Clementi M, Cocchi G, de Walle HE, Halliday J, Leoncini E, Li Z, Lowry RB, Marengo LK, Martínez-Frías ML, Merlob P, Morgan M, Muñoz LL, Rissmann A, Ritvanen A, Scarano G, Mastroiacovo P. Acardia: epidemiologic findings and literature review from the International Clearinghouse for Birth Defects Surveillance and Research. Am J Med Genet C Semin Med Genet. 2011 Nov 15;157C(4):262-73

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Mutchinick OM, Luna-Muñoz L, Amar E, Bakker MK, Clementi M, Cocchi G, da Graça Dutra M, Feldkamp ML, Landau D, Leoncini E, Li Z, Lowry B, Marengo LK, Martínez-Frías ML, Mastroiacovo P, Métneki J, Morgan M, Pierini A, Rissman A, Ritvanen A, Scarano G, Siffel C, Szabova E, Arteaga-Vázquez J. Conjoined twins: a worldwide collaborative epidemiological study of the International Clearinghouse for Birth Defects Surveillance and Research. Am J Med Genet C Semin Med Genet. 2011 Nov 15;157C (4):274-87.

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Siffel C, Correa A, Amar E, Bakker MK, Bermejo-Sánchez E, Bianca S, Castilla EE, Clementi M, Cocchi G, Csáky-Szunyogh M, Feldkamp ML, Landau D, Leoncini E, Li Z, Lowry RB, Marengo LK, Mastroiacovo P, Morgan M, Mutchinick OM, Pierini A, Rissmann A, Ritvanen A, Scarano G, Szabova E, Olney RS. Bladder exstrophy: an epidemiologic

study from the International Clearinghouse for Birth Defects Surveillance and Research, and an overview of the literature. Am J Med Genet C Semin Med Genet. 2011 Nov 5; 157C (4):321-32.

Luquetti DV, Leoncini E, Mastroiacovo P. Microtia-anotia: a global review of prevalence rates. Birth Defects Res A Clin Mol Teratol. 2011 Sep;91(9):813-22.

Argentina: RENAC

Barbero P, Liascovich R, Valdez R, Moresco A. [Misoprostol teratogenicity: a prospective study in Argentina].Arch Argent Pediatr. 2011 Jun;109(3):226-31.

Pardon F, Vilariño M, Barbero P, Garcia G, Outon E, Gil C, Vera A, Rossi S, Distefano A. Rubella vaccination of unknowingly pregnant women during 2006 mass campaign in Argentina. J Infect Dis. 2011 Sep 1;204 Suppl 2:S745-7

Colombia-Bogota: BCMSP

María Zarante A, García G, Zarante . Evaluación de factores de riesgo asociados con malformaciones congénitas en el programa de vigilancia epidemiológica demalformaciones congénitas (ECLAMC) en Bogotá entre 2001 y 2010 / Evaluation of risk factors associated with congenital malformations in the surveillance program of birth defects based on the methodology ECLAMC in Bogotá during the period 2001 to 2010. Univ. Med 53(1):11-25, ene.-mar. 2012. tab.

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