Annual Report 2013

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH (ICBDSR)

A non-governmental organisation in official relations
with the World Health Organization

Annual Report 2013

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Contents

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.).

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

2013 Tanya Bedard, Alberta Congenital Anomalies Surveillance System (ACASS), Alberta Health and Wellness, Canada

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.

Collaborative Research Projects

Multiple Congenital Anomalies 2011 Annual Report

by Monica Rittler and Jorge Lopez-Camelo

Introduction

For the year 2011, we received data from 5 programmes, 2 of which (Colombia and Wales) were not included in the analyses, due to lacking 1992-2000 baseline frequencies. The remaining 3 programmes reported a total of 879 cases, among 151,981 births (Table 1). Of these, 161 were reported as syndromes, while 347 had at least two major, unrelated congenital anomalies, which is our current case definition of multiple congenital anomalies (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, 39 were associated with an O/E ratio greater than 1. Eight 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 6 two-defects (Table 3) and for 1 three-defects combinations (Table 4).

For all comparisons, the data reported from 1992 through 2000, over 3,432,477 births were used as baseline.

Table 1: Cases of multiple congenital anomalies, by programme and number of defects (2011).

PROGRAMME	Births	Total cases Reported	Known etiology (syndromes)	<2 major unrelated defects	2 or +	Rate
Israel	44449	36	1	9	26	5.85
Mexico	14729	11	1	2	8	5.43
South America	92803	832	159	360	313	33.73
TOTAL	151981	879	161	371	347	22.83
Not included:						
Colombia	104967	194	24	98	72	6.86
Wales	35765	109	0	20	89	24.88

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

Malformation	Obs	Exp	Excess	Poisson
Congenital heart defects (CHD)	134	68.59	65.4	***
Urinary tract atresia/stenosis	59	28.16	30.8	***
Hydrocephaly	44	26.39	17.6	***
Other CNS defects	30	14.74	15.3	***
Other eye anomalies	20	6.42	13.6	***
Cystic kidneys	21	9.83	11.2	***
Pterygium colli, cystic hygroma	9	2.75	6.3	***
Spleen anomalies	6	0.89	5.1	***
Anencephaly	9	5.67	3.3	
Spina Bifida	14	11.11	2.9	
Encephalocele	14	7.48	6.5	
Microcephaly	18	12.31	5.7	
Holoprosencephaly	9	4.69	4.3	
An/microphthalmia	9	11.95	-3.0	
Severe ear defects	18	18.42	-0.4	
Dysplastic ears	3	0.8	2.2	
Cleft lip with/without cleft palate	41	29.58	11.4	
Cleft palate	21	20.01	1.0	
Other clefts and facial anomalies	2	6.91	-4.9	
Choanal atresia/stenosis	5	2.08	2.9	
Craniostenosis	1	1.9	-0.9	
Oesophageal atresia/stenosis	21	18.6	2.4	
Anorectal atresia/stenosis	40	31.57	8.4	
Duodenal atresia (without annular pancreas)	8	3.06	4.9	
Other gut atresia/stenosis	3	3.14	-0.1	
Malrotation of gut	0	1.77	-1.8	
Other intestinal anomalies	7	6.07	0.9	
Gastroschisis	9	4.47	4.5	
Omphalocele	15	14.12	0.9	
Diaphragmatic hernia	18	9.3	8.7	
Tracheo-bronchial-larynx atresia/stenosis	0	0.71	-0.7	
Other respiratory tract defects	10	5.36	4.6	
Vessel anomalies	2	0.35	1.7	
Hypospadias	16	11.6	4.4	
Genitalia defects (ambiguous and other)	17	16.25	0.8	
Kidney a/dysgenesis	20	11.69	8.3	
Extrophy of cloaca	2	1.73	0.3	
Sacrum anomalies	2	0.49	1.5	
Other axial skeleton defects	24	19.88	4.1	
Transverse limb reduction defects	6	8.01	-2.0	
Preaxial limb reduction defects	9	8.68	0.3	
Other limb reduction defects	13	7.13	5.9	
Polydactyly	33	25.33	7.7	
Syndactyly	17	8.55	8.5	
Club foot	60	43.92	16.1	
Ring constriction of limb(s)	0	0	0.0	
Situs inversus	2	1.64	0.4	
Other rare defects (Sacrococcygeal teratoma, sirenomelia)	2	1.99	0.0	

Table 3: Significant two-defects combinations.

Malformations	Obs	Exp	Excess	Poisson
Other eye anomalies + Club foot	6	0.93	5.1	***
Cleft lip with/without cleft palate + CHD	17	6.29	10.7	***
CHD + Urinary tract atresia/stenosis	27	9.34	17.7	***
CHD + Other limb reduction defects	6	0.80	5.2	***
Kidney a/dysgenesis + Polydactyly	5	0.58	4.4	***
Urinary tract atresia/stenosis + Syndactyly	4	0.27	3.7	***

***= p<0.001

Table 4: Significant three-defects combinations.

Malformations	Obs	Exp	Excess	Poisson
Spina bifida+Other intestinal anomalies+Cystic kidneys	2	0	2	***

*** p<0.001

Comments:

As usual, CHD were the anomalies most frequently found as single defects, as well as among the signficant two defects combinations. They were followed by urinary tract stenoses, hydrocephaly and other CNS anomalies, a distribution similar to previously reported periods.

The 2 observed cases with the significant three defects combination were diagnosed as having an OEIS association.

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

Rubella: 2 cases (SAM)
A05 B67 11: Hydrocephaly, cataracts and an ASD.
G11 213 11: Hydrocephaly with an abnormal corpus callosum, cataracts, and a complex heart defect.

Thalidomide: 1 case (SAM)
A39 097 11: Hypoplastic left radius and ulna with normal hand, left heart hypoplasia, facial asymmetry, microtia, and a thoracic hemivertebra.

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
Italy: BDRCam	Population-based Regional	1996	7 days	180 days (25 weeks + 5 days)	Permitted, Reported
Italy: IMER	Population-based Regional	1985	7 days	180 days (25 weeks + 5 days)	Permitted, Reported
Italy: North East	Population-based Regional	1997	7 days	180 days (25 weeks + 5 days)	Permitted, Reported
Italy: Lombardy-RMCL	Population-based Regional	2007	1 year	180 days (25 weeks + 5 days)	Permitted, Reported
Italy-Tuscany:RTDC	Population-based Regional	1998	1 year	180 days (25 weeks + 5 days)	Permitted, Reported

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
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	Hospital discharge	24 weeks or 500 grams	Permitted, Not reported on a routine basis by all the participating hospitals
Sweden	Population-based National	1974	28 days	22 weeks	Permitted, Reported
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
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.

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											25					35					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
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	47							8, 44		11,12	14	16	45	18	46		25			28,29						
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)
44 = includes pulmonary artery atresia with septal defect and Pentalogy of Fallot
45 = includes esophageal web
46 = includes imperforate anus
47 = does not include iniencephaly

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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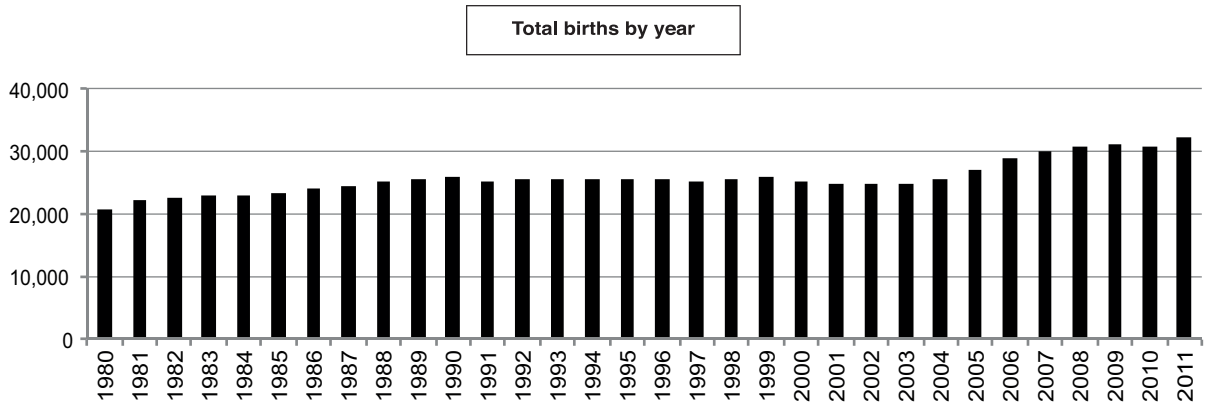
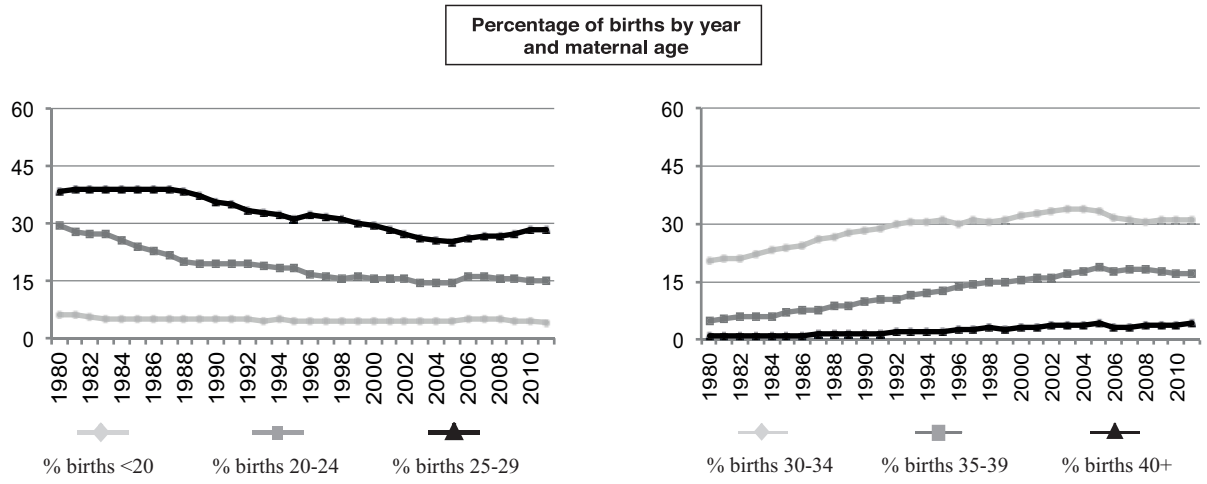
Website: http://kemh.health.wa.gov.au/services/register_developmental_anomalies/

Australia: WARDA





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	35	89.7	Cystic kidney	29	33.7
Spina bifida	38	67.9	Limb reduction defects	29	52.7
Encephalocele	16	84.2	Diaphragmatic hernia	13	32.5
Holoprosencephaly	8	72.7	Omphalocele	36	80.0
Hydrocephaly	42	65.6	Gastroschisis	1	2.9
Hypoplastic left heart syndrome	12	63.2	Trisomy 13	24	88.9
Cleft palate without cleft lip	8	9.4	Trisomy 18	58	77.3
Cleft lip with or without cleft palate	19	20.7	Down syndrome	202	70.4
Renal agenesis	20	39.2			

Total ToPs with births defects = 696 (Ratio ToPs/Births: 7.38 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: WARDA, 2011

Live births (LB)	31,907
Stillbirths (SB)	268
Total births	32,175
Number of terminations of pregnancy (ToP) for birth defects	237

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	10	3.73
Spina bifida	5	1	13	5.91
Encephalocele	1	0	7	2.49
Microcephaly	4	0	1	1.55
Holoprosencephaly	1	0	3	1.24
Hydrocephaly	3	4	19	8.08
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.93
Microtia	2	0	0	0.62
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	8	0	6	4.35
Tetralogy of Fallot	9	0	1	3.11
Hypoplastic left heart syndrome	1	1	3	1.55
Coarctation of aorta	9	0	0	2.80
Choanal atresia, bilateral	1	0	0	0.31
Cleft palate without cleft lip	19	1	3	7.15
Cleft lip with or without cleft palate	22	1	5	8.70
Oesophageal atresia/stenosis with or without fistula	13	0	1	4.35
Small intestine atresia/stenosis	8	0	0	2.49
Anorectal atresia/stenosis	8	0	2	3.11
Undescended testis (36 weeks of gestation or later)	63	0	0	19.58
Hypospadias	72	0	1	22.69
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	13	0	7	6.22
Cystic kidney	22	0	12	10.57
Bladder exstrophy	1	0	0	0.31
Polydactyly, preaxial	27	0	5	9.95
Total Limb reduction defects (include unspecified)	10	0	10	6.22
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	14	1	5	6.22
Omphalocele	5	2	11	5.59
Gastroschisis	12	0	1	4.04
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	9	2.80
Trisomy 18	2	4	18	7.46
Down syndrome, all ages (include age unknown)	21	0	71	28.59
<20	0	0	0	0.00
20-24	1	0	2	6.25
25-29	2	0	1	3.27
30-34	5	0	12	16.92
35-39	8	0	32	72.95
40-44	3	0	20	189.93
45+	2	0	4	810.81
unknown	2	0	1	---

nr = data not reported or not available

Australia: WARDA, Previous years rates 1980 - 2011

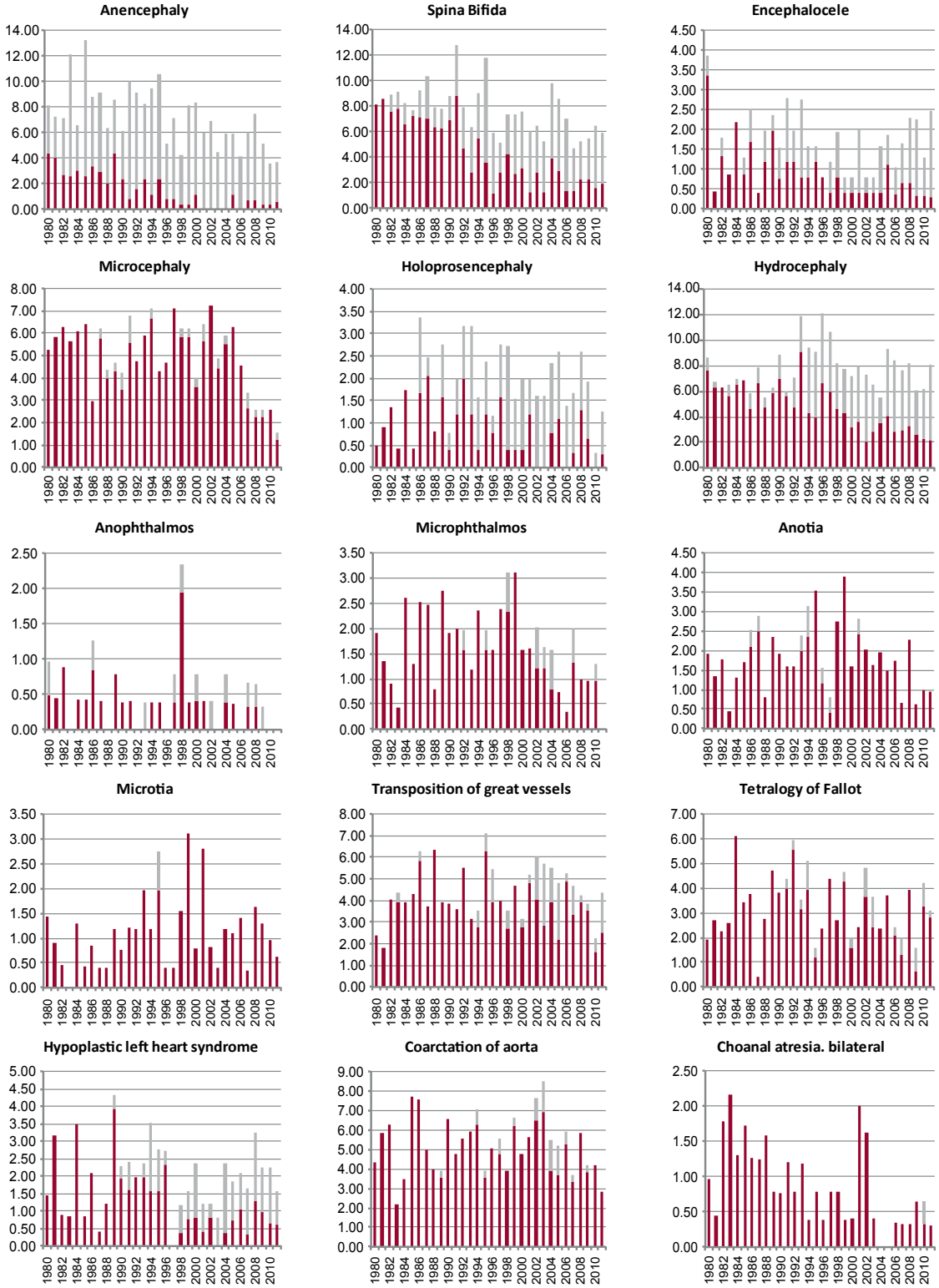
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**43,036**	**115,671**	**125,934**	**127,109**	**126,876**	**130,651**	**155,021**
Anencephaly		7.67	9.60	8.02	8.50	6.78	5.43	5.16
Spina bifida		8.37	8.65	9.53	8.18	6.70	7.42	5.55
Encephalocele		2.09	1.73	1.83	1.73	1.34	1.22	2.00
Microcephaly		5.58	5.45	5.24	5.35	5.99	5.74	2.52
Holoprosencephaly		0.70	1.47	1.75	2.28	2.21	1.91	1.55
Hydrocephaly		7.67	6.48	6.91	9.91	8.35	7.42	7.22
Anophthalmos		0.70	0.61	0.40	0.24	0.95	0.31	0.32
Microphthalmos		1.63	1.56	1.99	1.81	2.36	1.22	1.03
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00	0.06
Anotia		1.63	1.56	1.91	2.44	2.36	1.76	1.10
Microtia		1.16	0.61	0.79	1.49	1.73	1.00	0.97
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00	0.06
Transposition of great vessels		2.09	4.58	4.29	4.96	4.10	5.43	3.87
Tetralogy of Fallot		2.32	3.63	3.26	3.70	3.23	3.37	2.97
Hypoplastic left heart syndrome		2.32	1.64	2.14	2.67	1.26	1.68	2.19
Coarctation of aorta		5.11	5.45	4.84	5.51	5.28	6.51	4.13
Choanal atresia, bilateral		0.70	1.64	1.11	0.71	0.87	0.46	0.45
Cleft palate without cleft lip		7.67	9.34	8.81	10.86	12.45	10.56	8.90
Cleft lip with or without cleft palate		11.15	13.31	11.99	11.09	12.77	12.86	10.71
Oesophageal atresia/stenosis with or without fistula		4.18	2.25	3.65	2.91	3.23	4.44	4.06
Small intestine atresia/stenosis		3.95	2.59	2.70	2.05	3.07	2.68	2.97
Anorectal atresia/stenosis		6.04	4.75	5.96	7.00	6.23	6.51	4.64
Undescended testis (36 weeks of gestation or later)		65.53	64.93	69.56	62.07	55.17	41.79	24.96
Hypospadias		23.47	30.43	29.14	36.03	38.46	33.91	28.19
Epispadias		0.46	0.17	0.40	0.24	0.24	0.15	0.26
Indeterminate sex		0.00	0.17	0.32	0.24	0.16	0.15	0.06
Renal agenesis		2.32	4.06	3.65	4.25	4.89	5.28	4.90
Cystic kidney		2.79	3.11	5.08	7.71	8.99	8.50	8.58
Bladder exstrophy		0.00	0.17	0.40	0.16	0.47	0.15	0.19
Polydactyly, preaxial		7.90	10.46	10.56	12.19	11.27	12.17	9.68
Total Limb reduction defects (include unspecified)		4.65	4.93	6.19	6.69	10.33	8.80	6.26
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		4.88	2.42	3.02	3.78	4.02	3.75	3.48
Omphalocele		1.86	2.51	2.94	3.30	3.39	5.13	4.19
Gastroschisis		1.16	1.64	1.99	2.91	3.94	3.67	3.87
Unspecified Omphalocele/Gastroschisis		0.00	0.00	0.00	0.00	0.00	0.00	0.06
Prune belly sequence		0.46	0.69	0.40	0.63	0.16	0.00	0.13
Trisomy 13		0.46	0.86	0.95	1.81	2.36	3.29	2.97
Trisomy 18		1.63	1.47	2.94	3.93	6.70	7.65	7.55
Down syndrome, all ages (include age unknown)		10.46	13.66	15.25	19.43	21.52	27.10	28.77
<20		0.00	9.71	6.21	8.15	8.40	13.14	4.12
20-24		4.86	4.43	8.72	6.86	6.44	7.56	7.84
25-29		9.03	8.86	7.51	8.98	11.50	9.64	10.25
30-34		13.63	15.13	13.92	19.19	17.10	19.71	17.58
35-39		33.07	49.51	42.22	42.02	44.10	57.06	63.54
40-44		81.52	183.04	183.49	183.67	149.00	160.93	212.17
45+		833.33	483.87	447.76	408.16	397.73	516.43	431.03
unknown		---	---	---	---	---	---	---

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

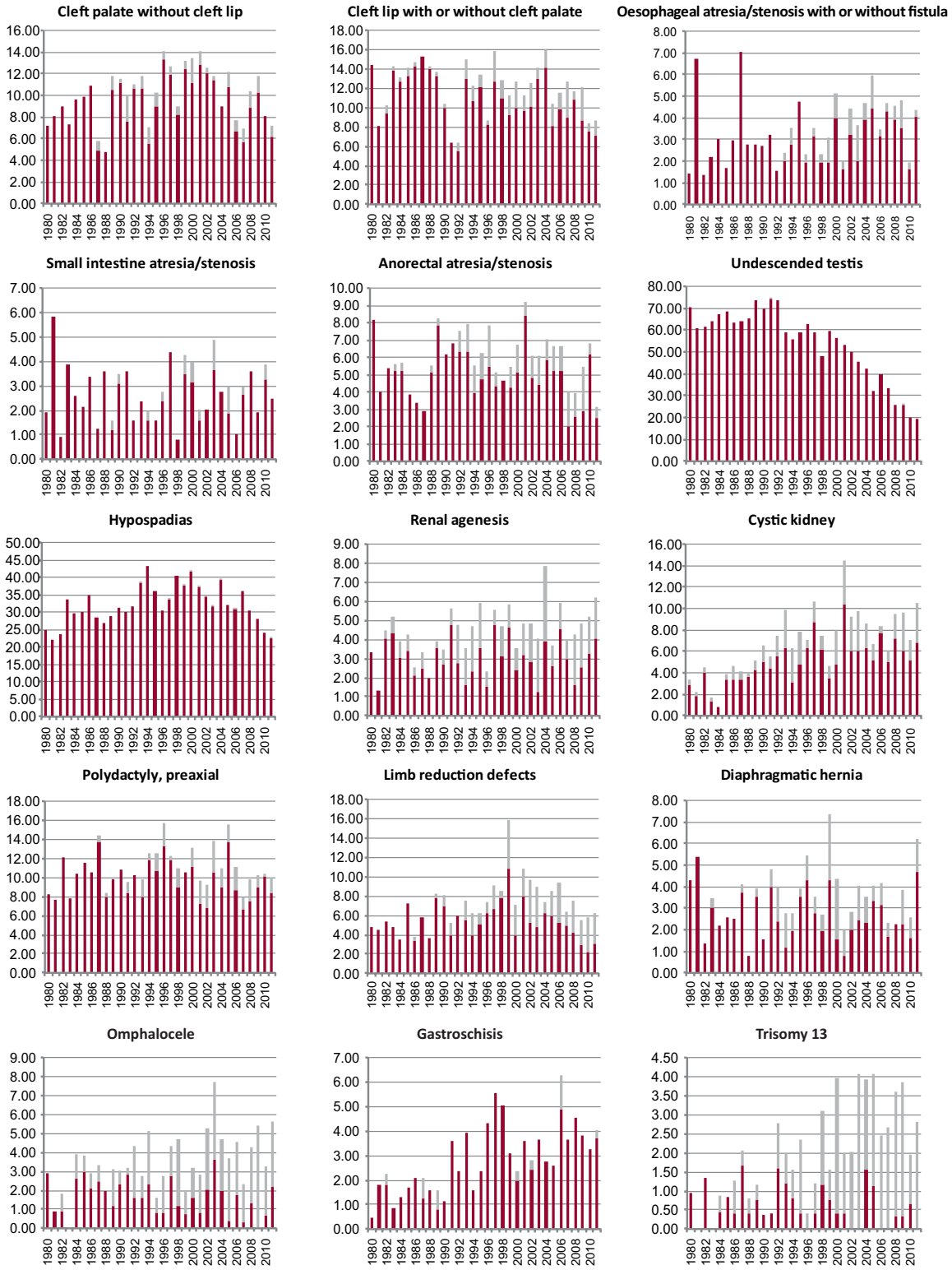
Australia: WARDA

Time trends 1980-2011 (Birth prevalence rates per 10,000)



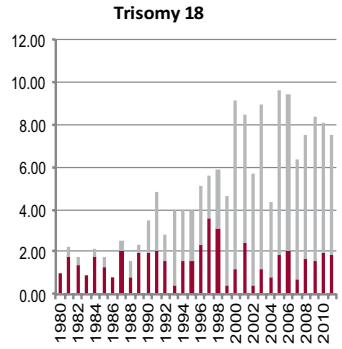
Note: L+S rates, ToP rates

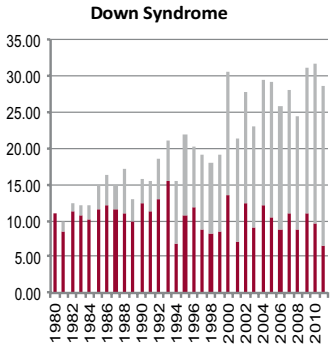
Australia: WARDA

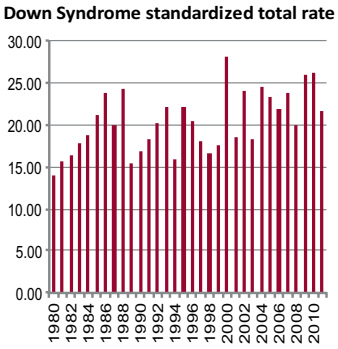


Note: L+S rates, ToP rates

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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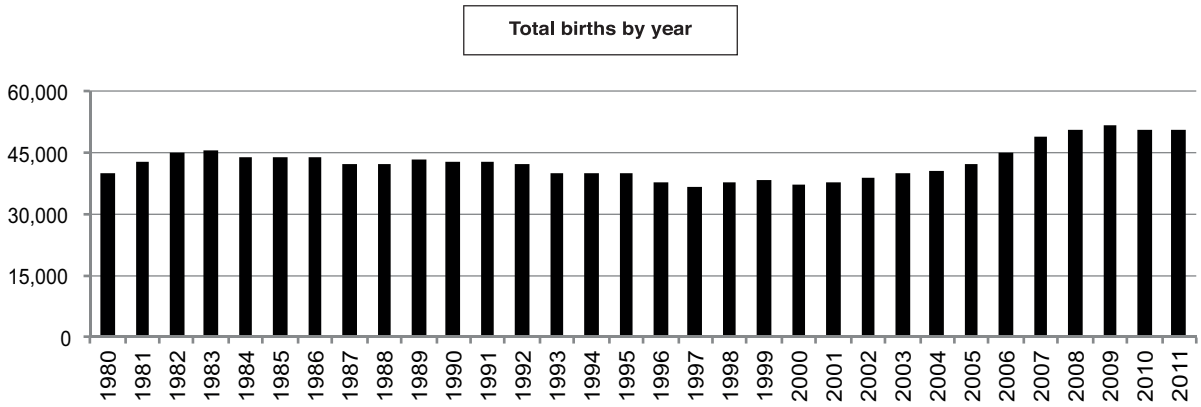
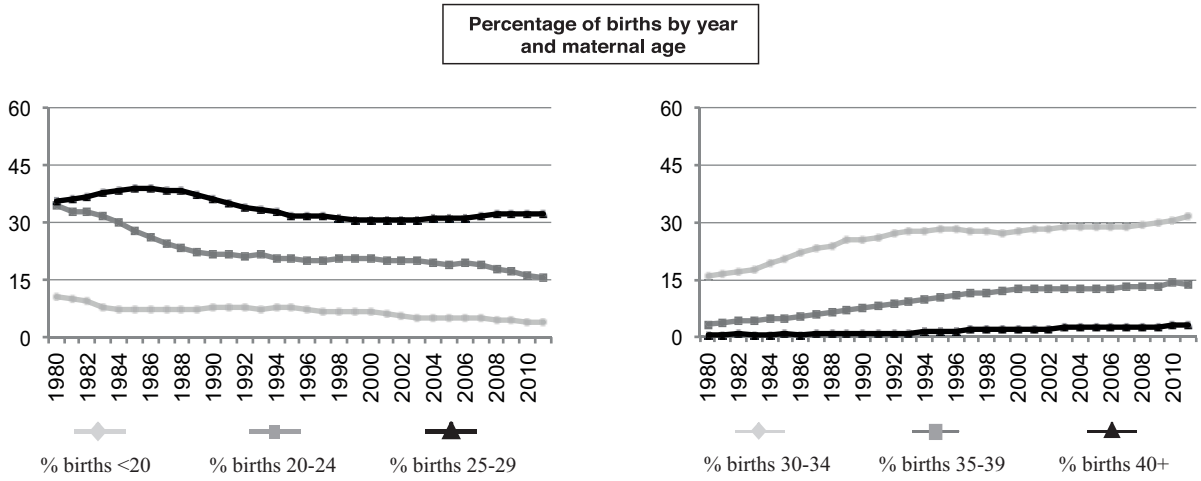
Canada-Alberta: ACASS





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	21	48.8	Cystic kidney	12	10.4
Spina bifida	10	15.2	Limb reduction defects	48	24.4
Encephalocele	3	15.0	Diaphragmatic hernia	4	7.1
Holoprosencephaly	17	48.6	Omphalocele	29	40.3
Hydrocephaly	9	9.4	Gastroschisis	2	2.7
Hypoplastic left heart syndrome	4	8.3	Trisomy 13	23	53.5
Cleft palate without cleft lip	8	7.4	Trisomy 18	45	49.5
Cleft lip with or without cleft palate	11	5.4	Down syndrome	118	33.5
Renal agenesis	2	9.1			

Total ToPs with births defects = 407 (Ratio ToPs/Births: 2.67 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Canada-Alberta: ACASS, 2011

Live births (LB)	50,413
Stillbirths (SB)	252
Total births	50,665
Number of terminations of pregnancy (ToP) for birth defects	130

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	5	10	3.16
Spina bifida	11	6	3	3.95
Encephalocele	4	0	1	0.99
Microcephaly	29	2	2	6.51
Holoprosencephaly	3	3	5	2.17
Hydrocephaly	24	12	3	7.70
Anophthalmos	1	1	0	0.39
Microphthalmos	5	0	1	1.18
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	11	0	0	2.17
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	15	5	0	3.95
Tetralogy of Fallot	14	4	0	3.55
Hypoplastic left heart syndrome	9	7	2	3.55
Coarctation of aorta	22	1	0	4.54
Choanal atresia, bilateral	1	0	0	0.20
Cleft palate without cleft lip	33	3	0	7.11
Cleft lip with or without cleft palate	54	5	2	12.04
Oesophageal atresia/stenosis with or without fistula	17	2	1	3.95
Small intestine atresia/stenosis	8	0	0	1.58
Anorectal atresia/stenosis	14	1	1	3.16
Undescended testis (36 weeks of gestation or later)	137	0	0	27.04
Hypospadias	126	0	0	24.87
Epispadias	5	0	0	0.99
Indeterminate sex	6	1	1	1.58
Renal agenesis	4	6	0	1.97
Cystic kidney	29	4	2	6.91
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	86	3	4	18.36
Total Limb reduction defects (include unspecified)	42	21	9	14.21
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	5	1	3.36
Omphalocele	9	7	8	4.74
Gastroschisis	26	2	1	5.72
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.20
Trisomy 13	3	3	6	2.37
Trisomy 18	4	10	11	4.93
Down syndrome, all ages (include age unknown)	58	14	47	23.49
<20	0	0	0	0.00
20-24	5	1	2	10.20
25-29	10	0	6	9.86
30-34	15	2	9	16.23
35-39	14	9	17	56.55
40-44	14	2	10	182.97
45+	0	0	3	315.79
unknown	0	0	0	---

nr = data not reported or not available

Canada-Alberta: ACASS, Previous years rates 1980 - 2011

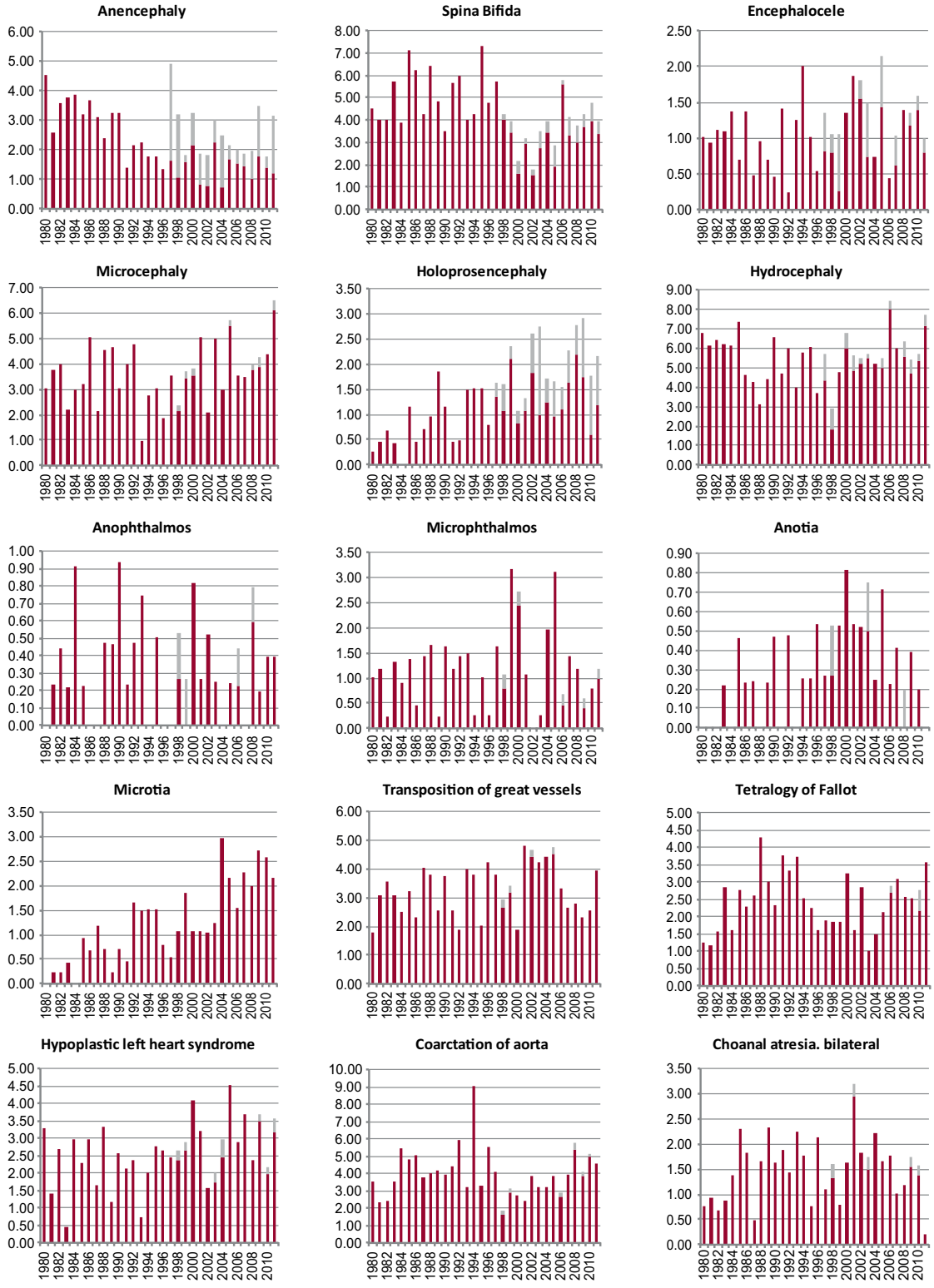
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**82,118**	**221,364**	**212,703**	**199,308**	**186,870**	**206,076**	**251,895**
Anencephaly		3.53	3.61	2.68	1.86	3.00	2.28	2.46
Spina bifida		4.26	5.38	4.94	5.27	3.85	3.64	4.17
Encephalocele		0.97	1.13	0.80	1.00	1.34	1.31	1.27
Microcephaly		3.41	3.48	3.67	2.71	3.69	3.88	4.53
Holoprosencephaly		0.37	0.54	1.03	1.15	1.61	2.04	2.38
Hydrocephaly		6.45	6.14	4.61	5.12	5.14	6.11	6.23
Anophthalmos		0.12	0.36	0.42	0.35	0.37	0.29	0.36
Microphthalmos		1.10	0.86	1.22	0.90	1.93	1.21	1.03
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.00	0.18	0.19	0.30	0.54	0.49	0.24
Microtia		0.12	0.45	0.66	1.40	1.12	1.80	2.34
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		2.44	2.94	3.34	3.16	3.37	4.27	2.86
Tetralogy of Fallot		1.22	2.21	3.20	2.71	2.09	2.09	2.90
Hypoplastic left heart syndrome		2.31	2.26	2.16	2.11	3.05	2.81	3.10
Coarctation of aorta		2.92	4.25	4.09	5.42	2.84	3.40	4.68
Choanal atresia, bilateral		0.85	1.40	1.60	1.66	1.66	1.84	1.15
Cleft palate without cleft lip		6.45	6.01	8.51	7.53	9.15	7.23	6.91
Cleft lip with or without cleft palate		10.11	10.39	12.74	11.94	11.34	11.94	13.89
Oesophageal atresia/stenosis with or without fistula		1.46	2.94	3.34	2.06	2.46	2.38	2.58
Small intestine atresia/stenosis		0.61	0.81	1.41	1.30	2.09	1.36	1.59
Anorectal atresia/stenosis		2.80	3.70	5.69	4.92	5.99	5.82	3.85
Undescended testis (36 weeks of gestation or later)		25.21	26.79	30.32	23.78	23.60	25.96	27.31
Hypospadias		16.68	19.20	25.43	21.57	19.37	20.19	23.30
Epispadias		0.61	0.41	0.38	0.40	0.54	0.73	0.83
Indeterminate sex		0.24	0.41	0.89	0.90	1.66	1.31	1.31
Renal agenesis		2.19	2.48	2.49	1.56	1.61	1.46	1.47
Cystic kidney		0.85	3.12	4.51	5.17	5.78	8.49	7.19
Bladder exstrophy		0.12	0.36	0.28	0.25	0.48	0.34	0.36
Polydactyly, preaxial		11.08	9.67	16.27	14.55	12.31	17.47	18.82
Total Limb reduction defects (include unspecified)		6.09	7.18	9.92	9.63	12.20	10.92	12.39
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		3.29	3.57	2.87	2.61	3.80	3.35	3.69
Omphalocele		0.97	1.90	2.59	1.51	2.57	2.62	4.09
Gastroschisis		1.22	1.54	1.46	1.91	2.68	4.56	4.84
Unspecified Omphalocele/Gastroschisis		0.61	0.59	0.42	0.25	0.00	0.00	0.00
Prune belly sequence		0.61	0.41	0.28	0.05	0.48	0.49	0.24
Trisomy 13		0.73	0.72	1.03	1.10	1.66	2.18	3.10
Trisomy 18		1.34	1.63	1.93	2.51	4.44	4.80	5.64
Down syndrome, all ages (include age unknown)		10.11	8.81	10.86	10.44	17.61	21.35	22.47
<20		nr	3.14	6.21	3.29	7.93	10.03	6.97
20-24		nr	6.98	5.76	5.76	4.98	7.16	8.09
25-29		nr	6.52	6.34	7.26	10.32	10.44	10.14
30-34		nr	6.28	15.01	11.62	16.08	16.01	18.19
35-39		nr	39.46	31.13	25.99	42.05	55.95	51.22
40-44		nr	186.92	90.25	67.17	162.27	179.95	184.17
45+		nr	0.00	307.69	266.67	260.87	377.36	323.45
unknown		---	---	---	---	---	---	---

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

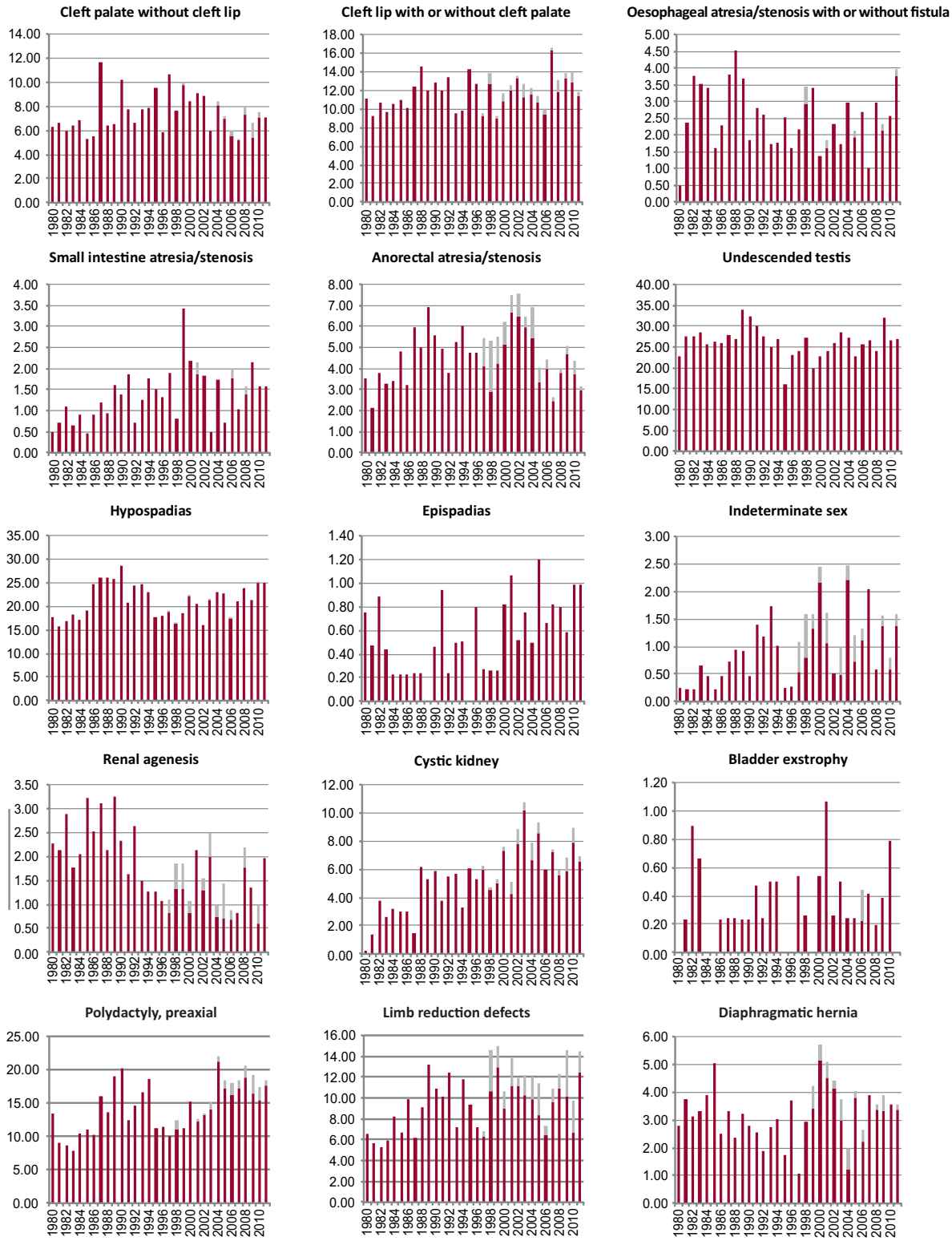
Canada-Alberta: ACASS

Time trends 1980-2011 (Birth prevalence rates per 10,000)



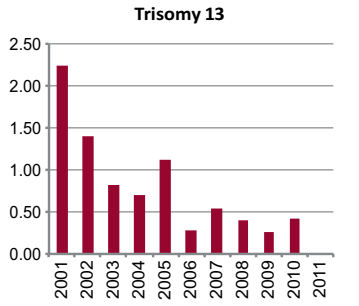
Note: L+S rates, ToP rates

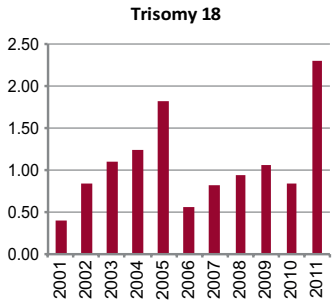
Canada-Alberta: ACASS

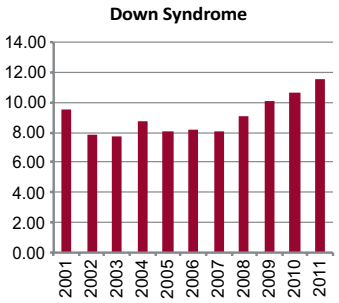


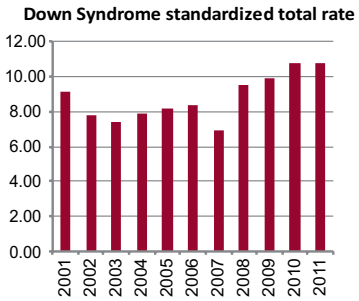
Note: L+S rates, ToP rates

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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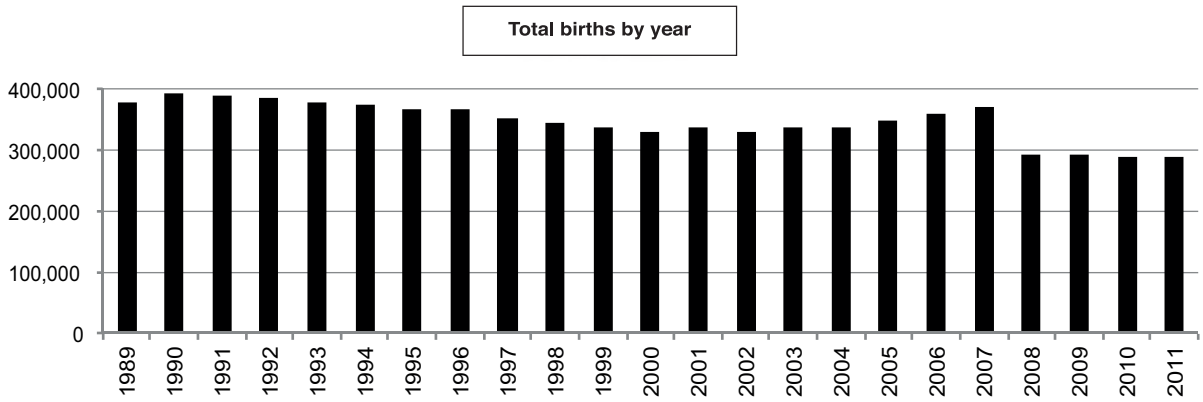
Canada National: CCASS



Canada National: CCASS, 2011(*)

Live births (LB)	284,943
Stillbirths (SB)	2,305
Total births	287,248
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	15	20	nr	1.22
Spina bifida	88	22	nr	3.83
Encephalocele	9	8	nr	0.59
Microcephaly	143	4	nr	5.12
Holoprosencephaly	15	12	nr	0.94
Hydrocephaly	117	22	nr	4.84
Anophthalmos	6	0	nr	0.21
Microphthalmos	16	0	nr	0.56
Unspecified Anophthalmos/Microphthalmos	20	0	nr	0.70
Anotia	1	0	nr	0.03
Microtia	20	0	nr	0.70
Unspecified Anotia/Microtia	21	0	nr	0.73
Transposition of great vessels	132	2	nr	4.66
Tetralogy of Fallot	93	8	nr	3.52
Hypoplastic left heart syndrome	56	12	nr	2.37
Coarctation of aorta	136	1	nr	4.77
Choanal atresia, bilateral	57	0	nr	1.98
Cleft palate without cleft lip	170	1	nr	5.95
Cleft lip with or without cleft palate	250	10	nr	9.05
Oesophageal atresia/stenosis with or without fistula	77	1	nr	2.72
Small intestine atresia/stenosis	96	2	nr	3.41
Anorectal atresia/stenosis	104	0	nr	3.62
Undescended testis (**)	968	0	nr	33.70
Hypospadias	809	0	nr	28.16
Epispadias	25	0	nr	0.87
Indeterminate sex	38	1	nr	1.36
Renal agenesis	124	12	nr	4.73
Cystic kidney	180	11	nr	6.65
Bladder exstrophy	4	0	nr	0.14
Polydactyly, preaxial	362	2	nr	12.67
Total Limb reduction defects (include unspecified)	86	3	nr	3.10
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	74	12	nr	2.99
Omphalocele	35	10	nr	1.57
Gastroschisis	121	7	nr	4.46
Unspecified Omphalocele/Gastroschisis	155	17	nr	5.99
Prune belly sequence	0	0	nr	0.00
Trisomy 13	16	23	nr	1.36
Trisomy 18	31	34	nr	2.26
Down syndrome, all ages (include age unknown)	379	65	nr	15.46
<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

nr = data not reported or not available
(*) Province of Quebec excluded
(**) No information on gestation age

Canada National: CCASS, Previous years rates 1989 - 2011

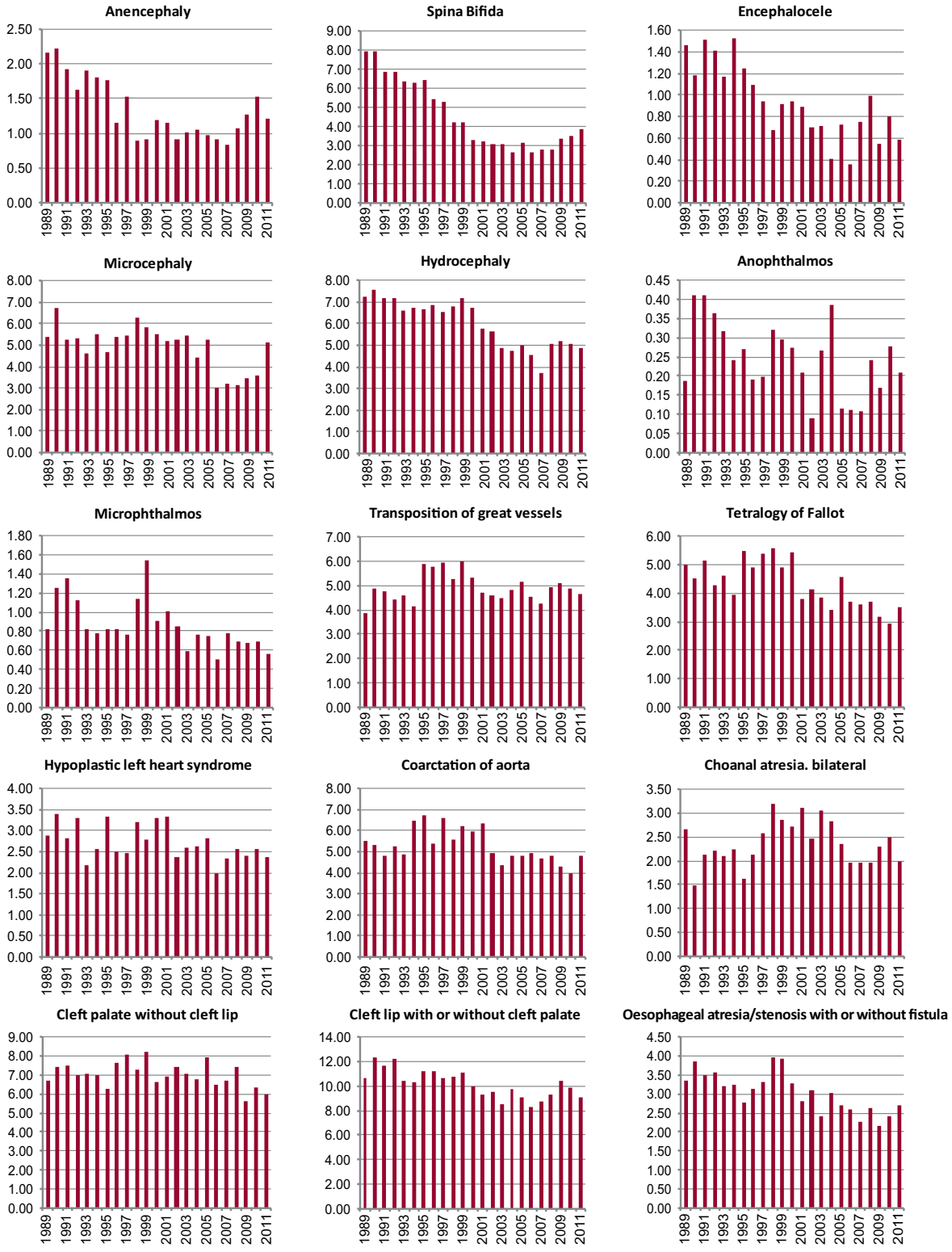
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991*	1992-1996	1997-2001	2002-2006	2007-2011
Total births				**1,156,605**	**1,872,269**	**1,698,115**	**1,710,260**	**1,529,025**
Anencephaly				2.10	1.66	1.14	0.98	1.16
Spina bifida				7.58	6.30	4.08	2.94	3.24
Encephalocele				1.38	1.29	0.87	0.58	0.74
Microcephaly				5.78	5.11	5.65	4.65	3.66
Holoprosencephaly				nr	nr	nr	0.36*	0.94
Hydrocephaly				7.31	6.80	6.60	4.95	4.70
Anophthalmos				0.34	0.28	0.26	0.19	0.20
Microphthalmos				1.15	0.87	1.07	0.69	0.69
Unspecified Anophthalmos/Microphthalmos				nr	nr	nr	nr	0.35*
Anotia				nr	nr	nr	0.11*	0.03
Microtia				nr	nr	nr	0.59*	0.97
Unspecified Anotia/Microtia				nr	nr	nr	nr	0.36*
Transposition of great vessels				4.51	4.96	5.45	4.72	4.74
Tetralogy of Fallot				4.87	4.62	5.02	3.94	3.39
Hypoplastic left heart syndrome				3.03	2.78	3.02	2.47	2.44
Coarctation of aorta				5.20	5.74	6.13	4.75	4.53
Choanal atresia, bilateral				2.08	2.06	2.89	2.52	2.13
Cleft palate without cleft lip				7.20	6.96	7.41	7.13	6.42
Cleft lip with or without cleft palate				11.54	11.05	10.38	9.03	9.42
Oesophageal atresia/stenosis with or without fistula				3.57	3.18	3.46	2.75	2.42
Small intestine atresia/stenosis				3.55	3.42	3.75	3.87	3.77
Anorectal atresia/stenosis				5.48	4.86	4.90	4.10	3.72
Undescended testis (36 weeks of gestation or later)				35.69	32.86	34.72	38.67	34.43
Hypospadias				27.11	26.36	28.00*	25.19*	27.49
Epispadias				nr	nr	nr	0.61*	0.69
Indeterminate sex				0.78	0.60	0.75	1.13	1.43
Renal agenesis				4.98	4.94	5.11	5.19	4.94
Cystic kidney				4.44	5.43	6.50	7.26	6.89
Bladder exstrophy				0.45	0.38	0.35	0.39	0.24
Polydactyly, preaxial				12.44	11.39	12.70	14.38	13.15
Total Limb reduction defects (include unspecified)				4.80	4.49	3.95	3.68	3.29
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				3.59	3.75	3.67	3.17	3.15
Omphalocele				4.51	6.19*	nr	1.79*	2.13
Gastroschisis				nr	nr	nr	3.69*	4.23
Unspecified Omphalocele/Gastroschisis				nr	6.62*	5.90*	nr	2.99*
Prune belly sequence				nr	nr	nr	nr	nr
Trisomy 13				1.23	1.09	1.21	1.13	1.18
Trisomy 18				2.16	2.21	2.40	2.39	2.34
Down syndrome, all ages (include age unknown)				13.65	12.57	14.25	14.64	14.64
<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 = data not reported or not available
* data include less than 5 years

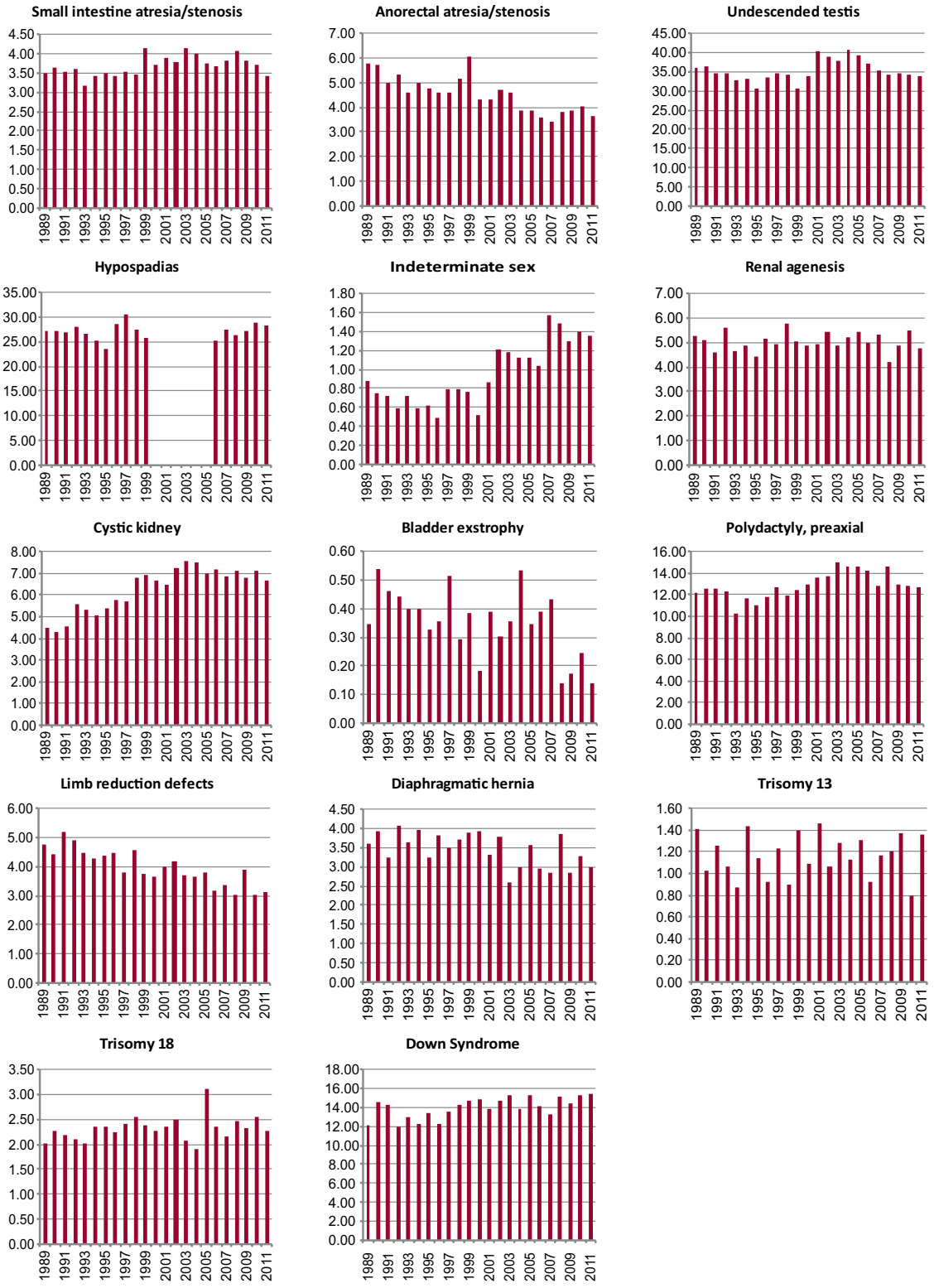
Canada National: CCASS

Time trends 1989-2011 (Birth prevalence rates per 10,000)



Note: L+S rates

Canada National: CCASS



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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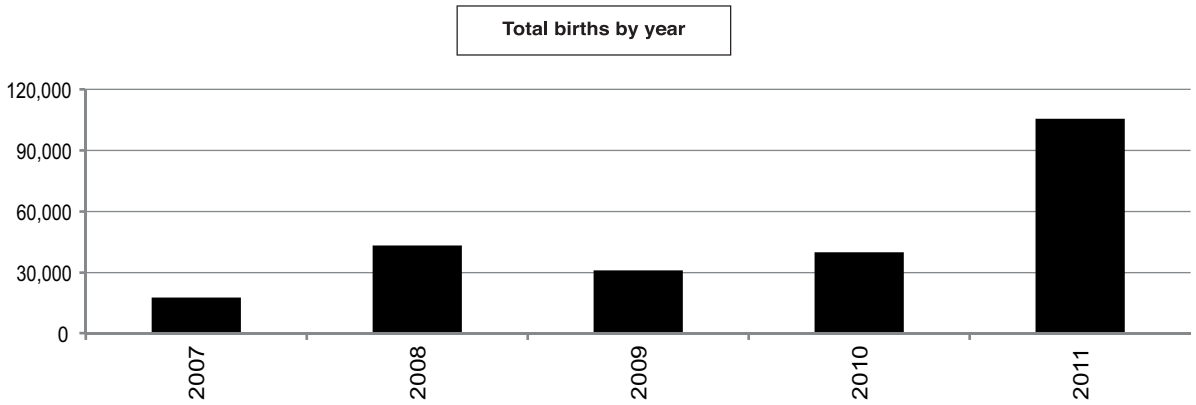
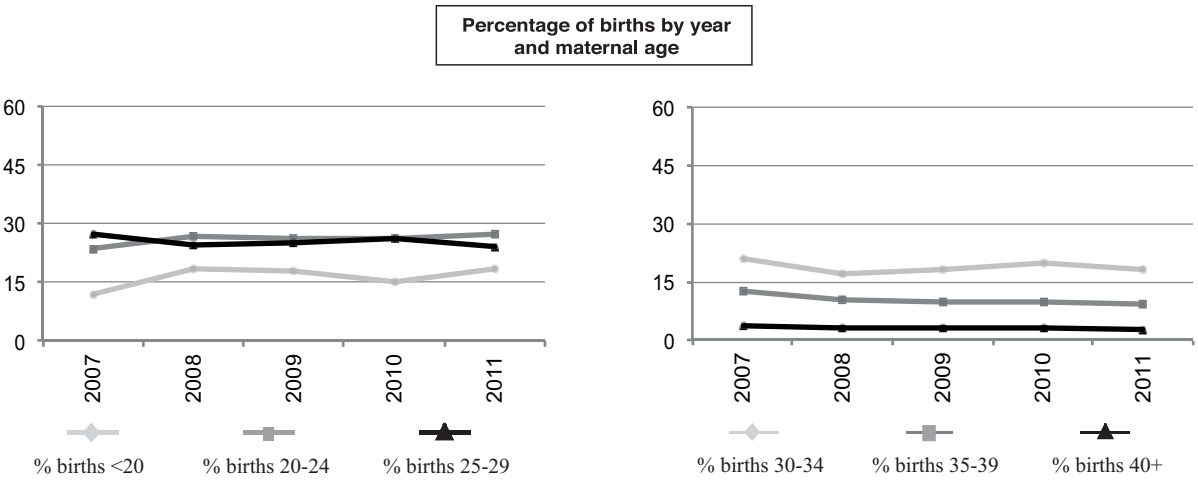
Colombia: CMSP





Colombia: CMSP, 2011

Live births (LB)	104,528
Stillbirths (SB)	439
Total births	104,967
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	6	0	nr	0.57
Spina bifida	18	0	nr	1.71
Encephalocele	2	0	nr	0.19
Microcephaly	7	0	nr	0.67
Holoprosencephaly	0	0	nr	0.00
Hydrocephaly	18	0	nr	1.71
Anophthalmos	1	0	nr	0.10
Microphthalmos	0	0	nr	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	42	0	nr	4.00
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	7	0	nr	0.67
Tetralogy of Fallot	3	0	nr	0.29
Hypoplastic left heart syndrome	8	1	nr	0.86
Coarctation of aorta	6	0	nr	0.57
Choanal atresia, bilateral	1	0	nr	0.10
Cleft palate without cleft lip	8	0	nr	0.76
Cleft lip with or without cleft palate	75	0	nr	7.15
Oesophageal atresia/stenosis with or without fistula	11	1	nr	1.14
Small intestine atresia/stenosis	2	0	nr	0.19
Anorectal atresia/stenosis	13	1	nr	1.33
Undescended testis (36 weeks of gestation or later)	15	0	nr	1.43
Hypospadias	21	0	nr	2.00
Epispadias	0	0	nr	0.00
Indeterminate sex	23	0	nr	2.19
Renal agenesis	4	0	nr	0.38
Cystic kidney	4	1	nr	0.48
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	25	2	nr	2.57
Total Limb reduction defects (include unspecified)	24	0	nr	2.29
Transverse	8	0	nr	0.76
Preaxial	1	0	nr	0.10
Postaxial	5	0	nr	0.48
Intercalary	2	0	nr	0.19
Mixed	6	0	nr	0.57
Unspecified	2	0	nr	0.19
Diaphragmatic hernia	16	0	nr	1.52
Omphalocele	12	0	nr	1.14
Gastroschisis	19	0	nr	1.81
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	2	0	nr	0.19
Trisomy 13	1	3	nr	0.38
Trisomy 18	3	3	nr	0.57
Down syndrome, all ages (include age unknown)	107	0	nr	10.19
<20	9	0	nr	4.72
20-24	18	0	nr	6.41
25-29	12	0	nr	4.80
30-34	13	0	nr	6.85
35-39	29	0	nr	30.33
40-44	22	0	nr	87.09
45+	2	0	nr	75.76
unknown	2	0	nr	---

nr = data not reported or not available

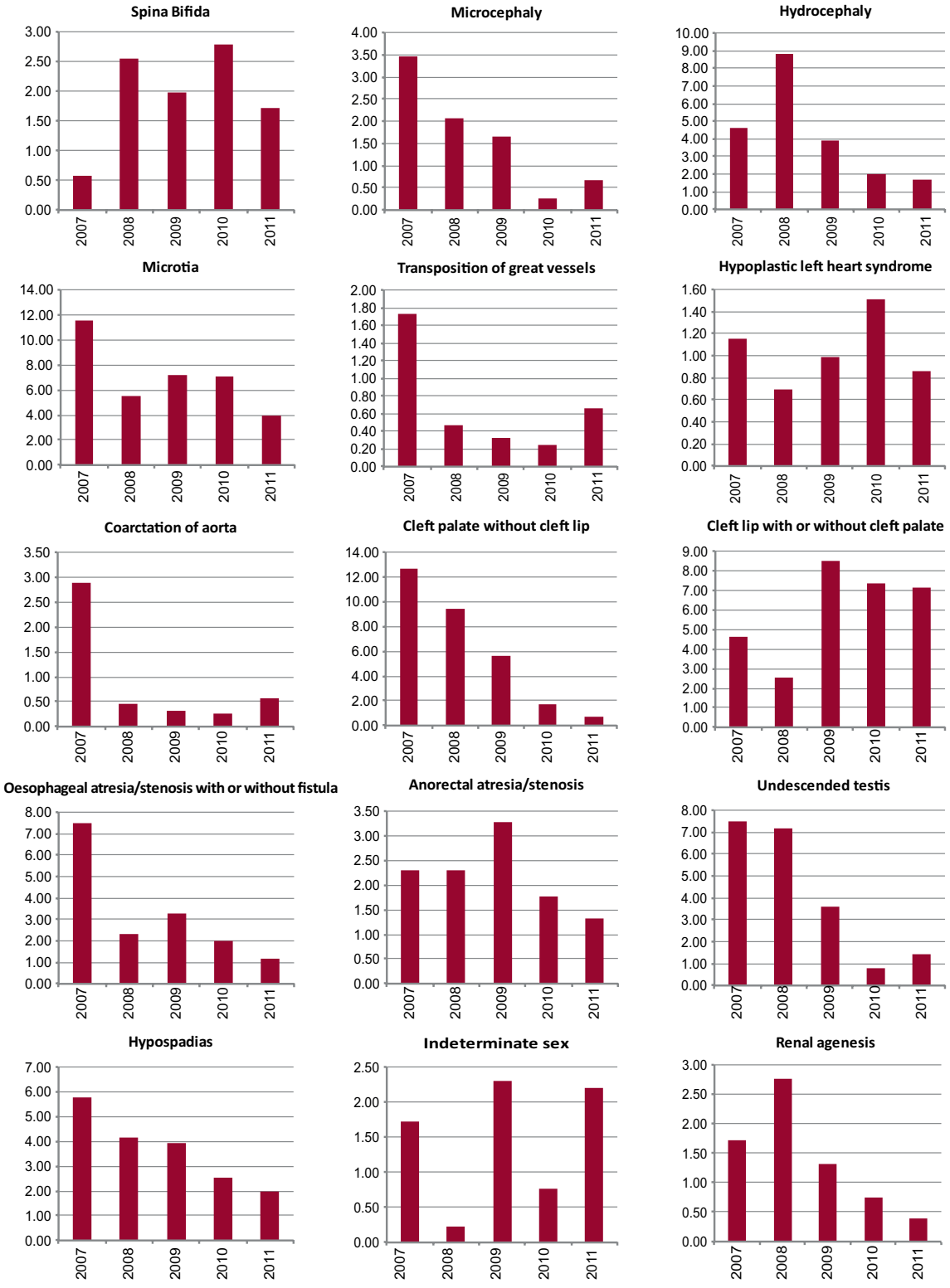
Colombia: CMSP, Previous years rates 2007 - 2011

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

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births								**235,715**
Anencephaly								0.64
Spina bifida								1.99
Encephalocele								0.17
Microcephaly								1.19
Holoprosencephaly								0.64
Hydrocephaly								3.56
Anophthalmos								0.13
Microphthalmos								0.25
Unspecified Anophthalmos/Microphthalmos								0.00
Anotia								0.00
Microtia								5.77
Unspecified Anotia/Microtia								0.04
Transposition of great vessels								0.59
Tetralogy of Fallot								0.38
Hypoplastic left heart syndrome								0.98
Coarctation of aorta								0.64
Choanal atresia, bilateral								0.25
Cleft palate without cleft lip								4.03
Cleft lip with or without cleft palate								6.32
Oesophageal atresia/stenosis with or without fistula								2.25
Small intestine atresia/stenosis								0.64
Anorectal atresia/stenosis								1.91
Undescended testis (36 weeks of gestation or later)								3.10
Hypospadias								3.01
Epispadias								0.08
Indeterminate sex								1.57
Renal agenesis								1.10
Cystic kidney								1.02
Bladder exstrophy								0.00
Polydactyly, preaxial								4.88
Total Limb reduction defects (include unspecified)								4.16
Transverse								0.59
Preaxial								0.04
Postaxial								0.42
Intercalary								0.08
Mixed								0.42
Unspecified								3.01
Diaphragmatic hernia								1.57
Omphalocele								1.44
Gastroschisis								1.87
Unspecified Omphalocele/Gastroschisis								0.00
Prune belly sequence								0.25
Trisomy 13								0.30
Trisomy 18								0.64
Down syndrome, all ages (include age unknown)								9.67
<20								5.59
20-24								3.82
25-29								6.17
30-34								7.33
35-39								30.58
40-44								85.47
45+								147.33
unknown								---

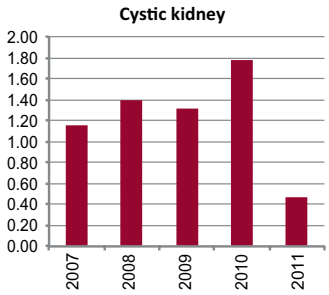
Colombia: CMSP

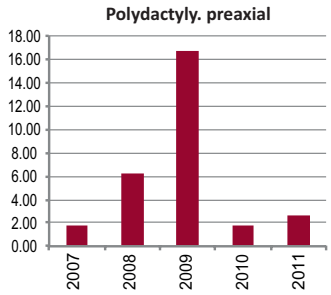
Time trends 2007-2011 (Birth prevalence rates per 10,000)

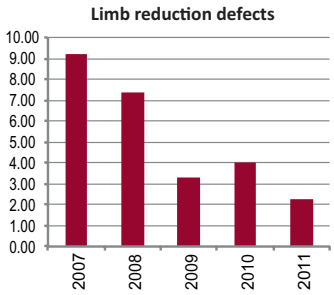


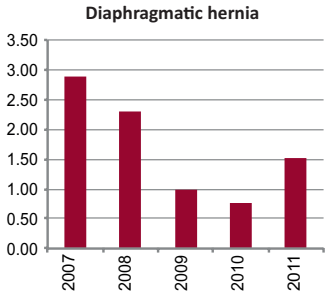
Note: L+S rates

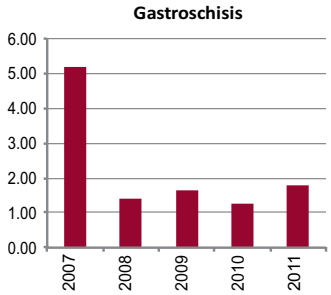
Colombia: CMSP

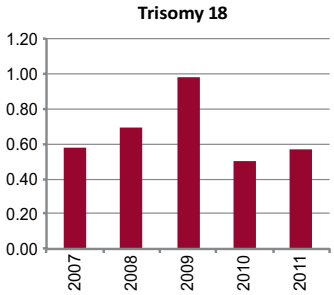


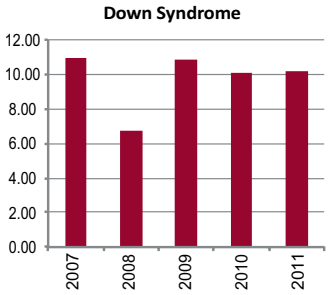


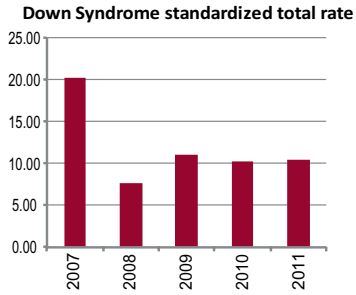












Note: L+S rates

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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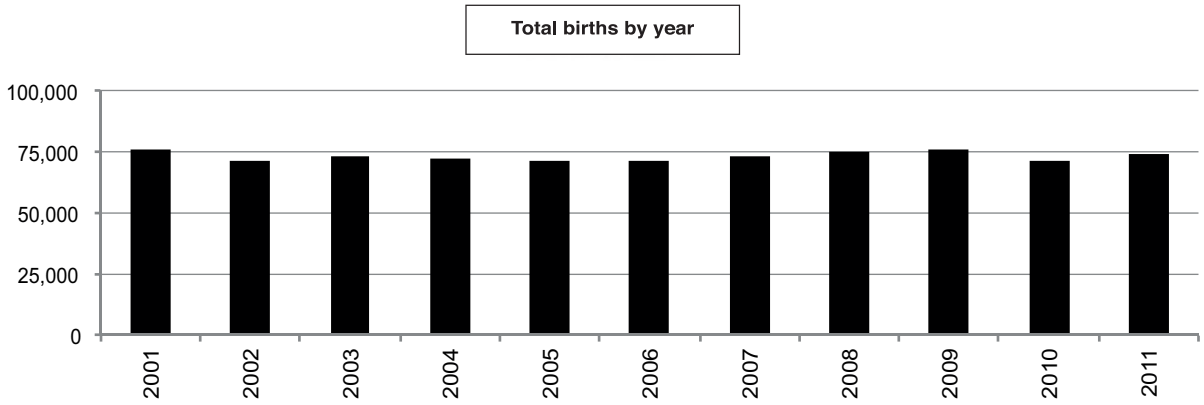
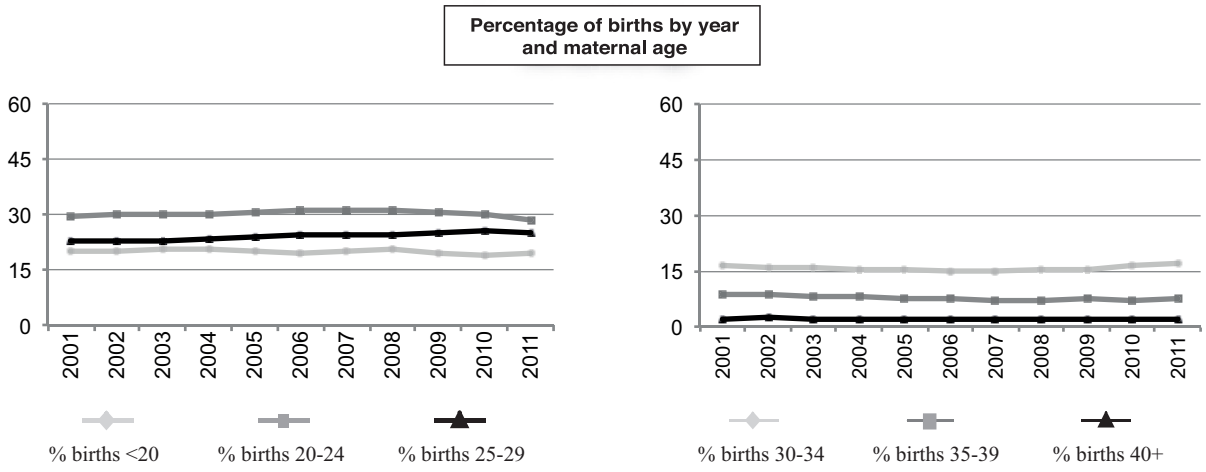
Costa Rica: CREC





Costa Rica: CREC, 2011

Live births (LB)	73,326
Stillbirths (SB)	465
Total births	73,791
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	12	1		1.76
Spina bifida	29	0		3.93
Encephalocele	5	0		0.68
Microcephaly	17	1		2.44
Holoprosencephaly	3	0		0.41
Hydrocephaly	37	1		5.15
Anophthalmos	7	0		0.95
Microphthalmos	7	0		0.95
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	4	0		0.54
Microtia	13	0		1.76
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	13	0		1.76
Tetralogy of Fallot	11	0		1.49
Hypoplastic left heart syndrome	4	0		0.54
Coarctation of aorta	18	0		2.44
Choanal atresia, bilateral	8	0		1.08
Cleft palate without cleft lip	23	0		3.12
Cleft lip with or without cleft palate	66	0		8.94
Oesophageal atresia/stenosis with or without fistula	21	1		2.98
Small intestine atresia/stenosis	20	0		2.71
Anorectal atresia/stenosis	30	1		4.20
Undescended testis (36 weeks of gestation or later)	107	1		14.64
Hypospadias	46	0		6.23
Epispadias	2	0		0.27
Indeterminate sex	12	1		1.76
Renal agenesis	7	1		1.08
Cystic kidney	4	0		0.54
Bladder exstrophy	0	0		0.00
Polydactyly(**)	91	1		12.47
Total Limb reduction defects (include unspecified)	44	2		6.23
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	23	0		3.12
Omphalocele	14	0		1.90
Gastroschisis	30	0		4.07
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	2	0		0.27
Trisomy 13	0	0		0.00
Trisomy 18	16	1		2.30
Down syndrome, all ages (include age unknown)	85	0		11.59
<20	9	0		6.34
20-24	11	0		5.27
25-29	9	0		4.90
30-34	14	0		11.12
35-39	14	0		25.43
40-44	19	0		136.89
45+	2	0		273.97
unknown	7	0		---

nr = data not reported or not available
(*) Birth defects under-reported in stillbirths
(**) All cases, no specification available

Costa Rica: CREC, Previous years rates 2001 - 2011

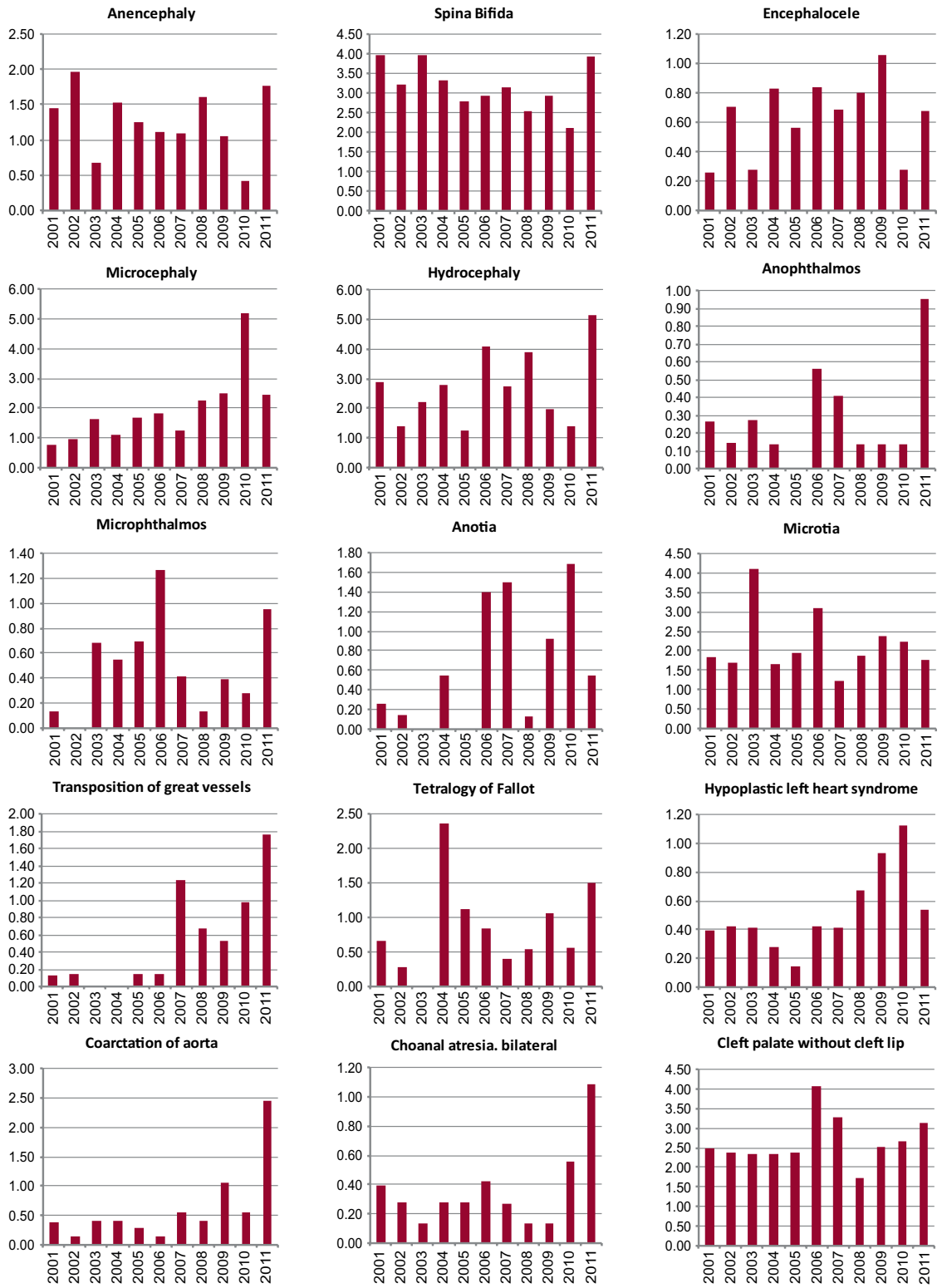
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001*	2002-2006	2007-2011
Total births						**75,991**	**359,168**	**368,578**
Anencephaly						1.45	1.31	1.19
Spina bifida						3.95	3.26	2.93
Encephalocele						0.26	0.64	0.71
Microcephaly						0.79	1.45	2.71
Holoprosencephaly						0.66	0.22	0.57
Hydrocephaly						2.90	2.34	3.04
Anophthalmos						0.26	0.22	0.35
Microphthalmos						0.13	0.64	0.43
Unspecified Anophthalmos/Microphthalmos						0.00	0.00	0.00
Anotia						0.26	0.42	0.95
Microtia						1.84	2.51	1.90
Unspecified Anotia/Microtia						0.00	0.00	0.14
Transposition of great vessels						0.13	0.08	1.03
Tetralogy of Fallot						0.66	0.92	0.81
Hypoplastic left heart syndrome						0.39	0.33	0.73
Coarctation of aorta						0.39	0.28	1.00
Choanal atresia, bilateral						0.39	0.28	0.43
Cleft palate without cleft lip						2.50	2.70	2.66
Cleft lip with or without cleft palate						7.24	6.77	7.71
Oesophageal atresia/stenosis with or without fistula						1.71	1.28	2.14
Small intestine atresia/stenosis						0.66	0.70	0.81
Anorectal atresia/stenosis						2.76	2.70	2.96
Undescended testis (36 weeks of gestation or later)						10.26	9.52	11.99
Hypospadias						5.92	6.15	6.86
Epispadias						0.13	0.06	0.11
Indeterminate sex						1.45	1.78	1.33
Renal agenesis						0.53	0.81	0.84
Cystic kidney						0.26	0.28	1.44
Bladder exstrophy						0.13	0.06	0.00
Polydactyly, preaxial						2.11	9.30	11.83
Total Limb reduction defects (include unspecified)						4.87	4.87	4.86
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						1.84	1.61	1.79
Omphalocele						0.13	0.86	1.36
Gastroschisis						2.24	1.34	2.79
Unspecified Omphalocele/Gastroschisis						0.00	0.17	0.00
Prune belly sequence						0.13	0.42	0.24
Trisomy 13						2.24	0.86	0.33
Trisomy 18						0.39	1.11	1.19
Down syndrome, all ages (include age unknown)						9.47	8.10	9.88
<20						5.17	4.84	5.30
20-24						4.43	4.87	3.87
25-29						4.59	4.27	4.27
30-34						4.83	5.58	9.68
35-39						31.17	26.28	30.10
40-44						121.48	66.12	111.13
45+						79.37	146.14	230.95
unknown						---	---	---

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

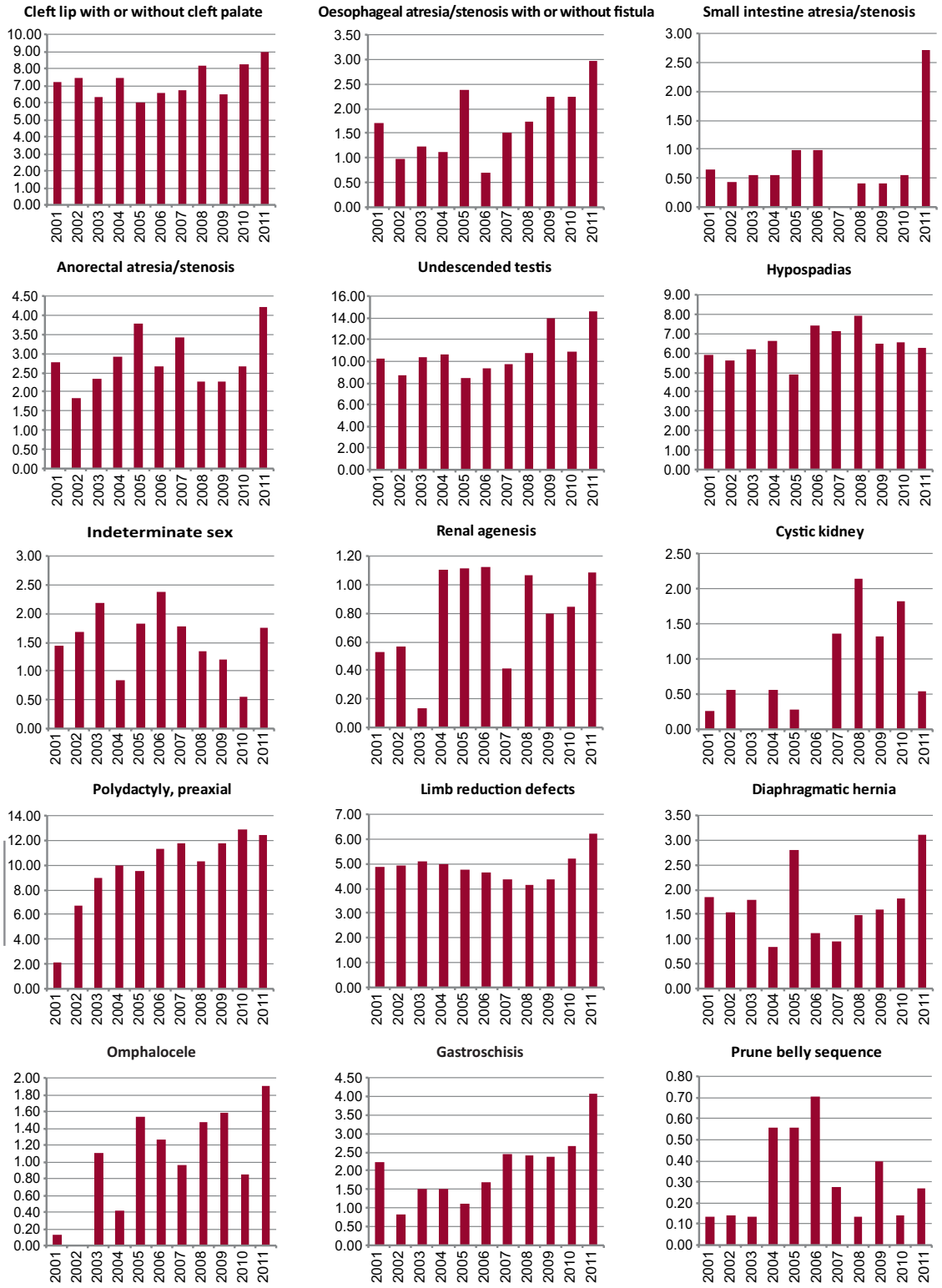
Costa Rica: CREC

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



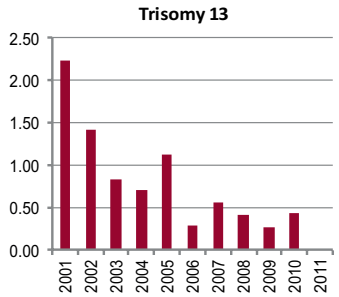
Note: L+S rates

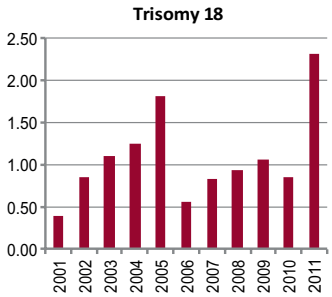
Costa Rica: CREC

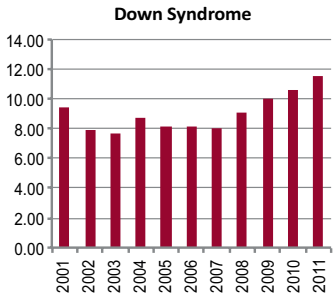


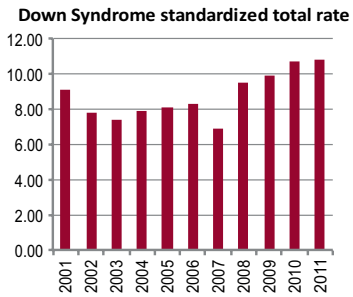
Note: L+S rates

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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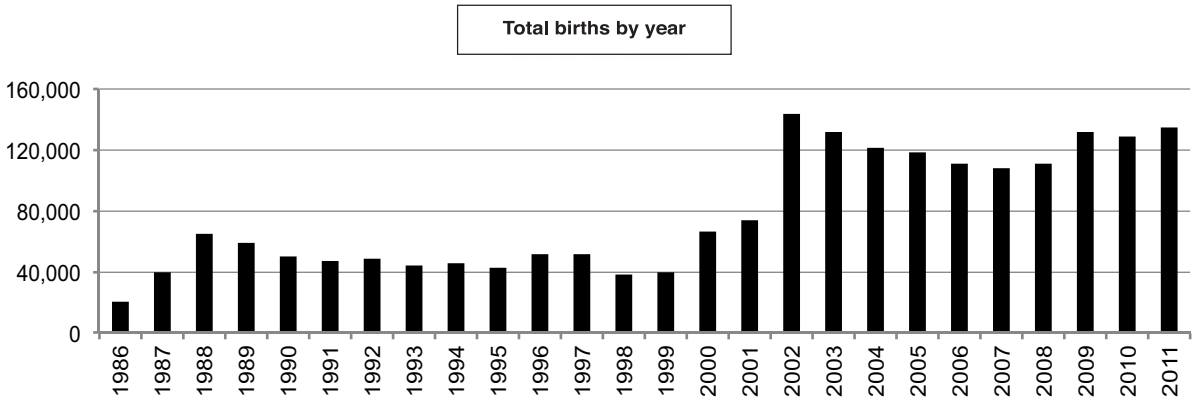
Cuba: RECUMAC



Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	165	98.2	Cystic kidney	112	78.3
Spina bifida	97	75.2	Limb reduction defects	23	30.7
Encephalocele	54	91.5	Diaphragmatic hernia	67	67.7
Holoprosencephaly	44	93.6	Omphalocele	90	85.7
Hydrocephaly	225	84.6	Gastroschisis	239	96.0
Hypoplastic left heart syndrome	71	86.6	Trisomy 13	20	100.0
Cleft palate without cleft lip	8	8.8	Trisomy 18	58	82.9
Cleft lip with or without cleft palate	55	29.7	Down syndrome	224	48.2
Renal agenesis	29	61.7			

Total ToPs with births defects = 3,955 (Ratio ToPs/Births: 10.01 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Cuba: RECUMAC, 2011

Live births (LB)	133,067
Stillbirths (SB)	1,412
Total births	134,479
Number of terminations of pregnancy (ToP) for birth defects	1,371

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	36	2.83
Spina bifida	14	0	34	3.57
Encephalocele	2	0	21	1.71
Microcephaly	3	0	0	0.22
Holoprosencephaly	0	0	17	1.26
Hydrocephaly	7	1	72	5.95
Anophthalmos	1	0	0	0.07
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	9	0	0	0.67
Microtia	3	0	0	0.22
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	9	1	14	1.78
Tetralogy of Fallot	15	0	17	2.38
Hypoplastic left heart syndrome	2	0	26	2.08
Coarctation of aorta	12	0	3	1.12
Choanal atresia, bilateral	2	0	0	0.15
Cleft palate without cleft lip	27	0	0	2.01
Cleft lip with or without cleft palate	37	0	23	4.46
Oesophageal atresia/stenosis with or without fistula	16	1	6	1.71
Small intestine atresia/stenosis	22	0	31	3.94
Anorectal atresia/stenosis	14	0	1	1.12
Undescended testis (36 weeks of gestation or later)	21	0	0	1.56
Hypospadias	112	0	0	8.33
Epispadias	3	0	0	0.22
Indeterminate sex	6	0	0	0.45
Renal agenesis	8	0	4	0.89
Cystic kidney	8	0	25	2.45
Bladder exstrophy	0	0	1	0.07
Polydactyly, preaxial	6	0	0	0.45
Total Limb reduction defects (include unspecified)	24	0	6	2.23
Transverse	6	0	1	0.52
Preaxial	2	0	0	0.15
Postaxial	2	0	1	0.22
Intercalary	3	0	0	0.22
Mixed	5	0	1	0.45
Unspecified	6	0	3	0.67
Diaphragmatic hernia	9	1	27	2.75
Omphalocele	9	0	29	2.83
Gastroschisis	4	1	86	6.77
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	6	0.45
Trisomy 18	4	0	20	1.78
Down syndrome, all ages (include age unknown)	88	0	66	11.45
<20	6	0	4	4.88
20-24	17	0	0	3.75
25-29	17	0	5	6.24
30-34	17	0	3	10.66
35-39	21	0	33	46.06
40-44	9	0	17	98.30
45+	0	0	4	258.06
unknown	1	0	0	---

Cuba: RECUMAC, Previous years rates 1986 - 2011

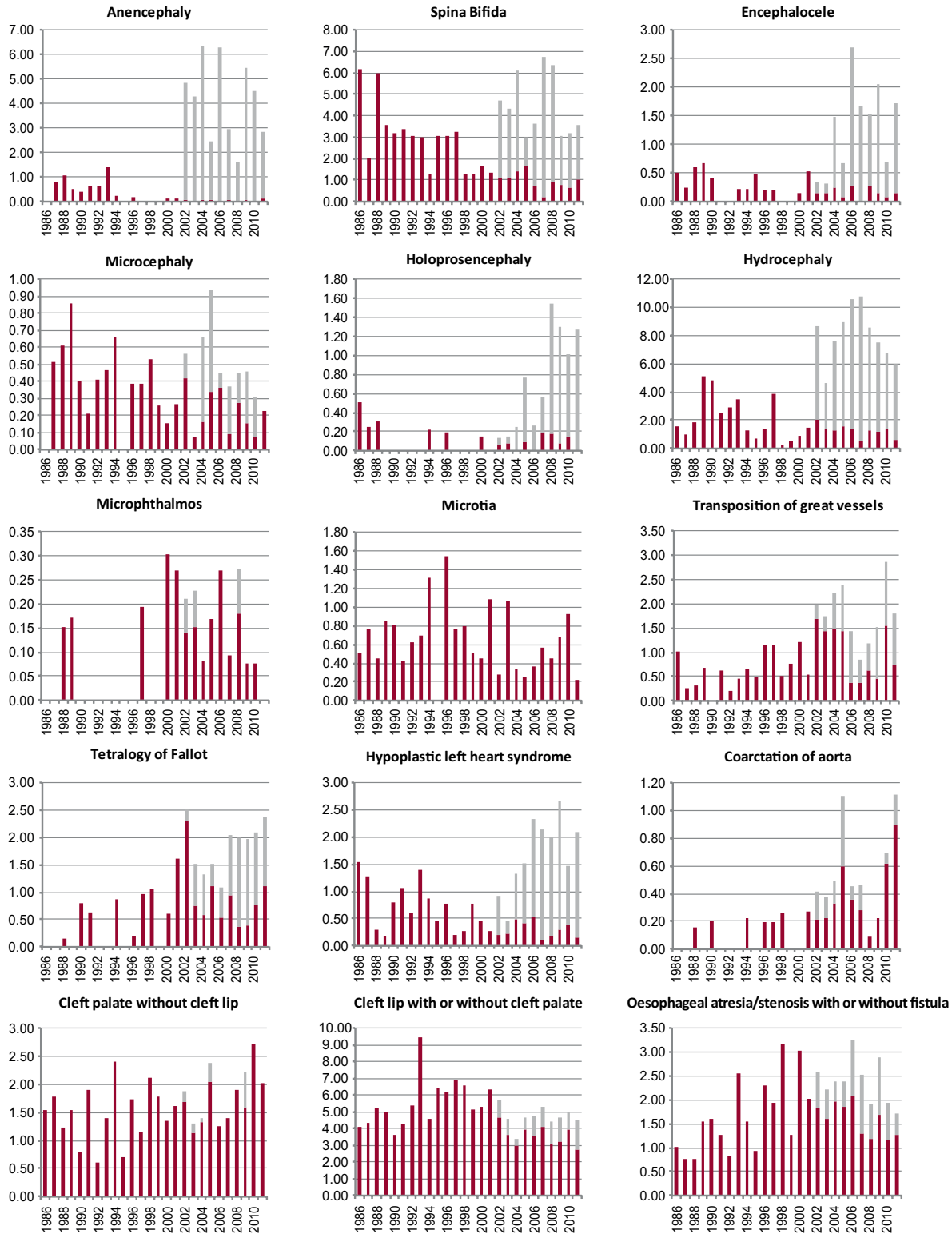
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986*	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births			**28,122**	**260,474**	**231,977**	**269,593**	**625,257**	**612,941**
Anencephaly			0.71	0.69	0.47	0.07	4.81	3.56
Spina bifida			8.89	3.84	2.72	1.78	4.37	4.42
Encephalocele			0.36	0.42	0.22	0.22	1.04	1.53
Microcephaly			0.36	0.54	0.39	0.30	0.53	0.36
Holoprosencephaly			0.71	0.12	0.09	0.04	0.30	1.14
Hydrocephaly			3.91	3.15	1.94	1.48	7.98	7.77
Anophthalmos			0.00	0.08	0.00	0.07	0.13	0.03
Microphthalmos			0.00	0.08	0.00	0.19	0.19	0.10
Unspecified Anophthalmos/Microphthalmos			0.00	0.00	0.00	0.00	0.05	0.02
Anotia			0.00	0.00	0.00	0.04	0.11	0.31
Microtia			1.42	0.65	0.86	0.74	0.46	0.57
Unspecified Anotia/Microtia			0.00	0.00	0.00	0.00	0.06	0.00
Transposition of great vessels			0.71	0.38	0.60	0.85	1.95	1.68
Tetralogy of Fallot			0.00	0.31	0.22	0.93	1.63	2.10
Hypoplastic left heart syndrome			1.42	0.65	0.82	0.37	1.26	2.07
Coarctation of aorta			0.00	0.08	0.09	0.15	0.56	0.54
Choanal atresia, bilateral			0.36	0.15	0.00	0.19	0.19	0.08
Cleft palate without cleft lip			1.42	1.42	1.38	1.56	1.65	2.07
Cleft lip with or without cleft palate			4.27	4.53	6.34	6.05	4.64	4.75
Oesophageal atresia/stenosis with or without fistula			1.42	1.19	1.64	2.30	2.54	2.19
Small intestine atresia/stenosis			1.42	0.73	0.69	0.74	1.66	3.05
Anorectal atresia/stenosis			2.49	1.07	1.51	1.34	1.25	1.16
Undescended testis (36 weeks of gestation or later)			4.62	3.80	4.66	2.08	2.86	2.17
Hypospadias			14.58	14.86	11.68	10.09	8.49	8.48
Epispadias			0.00	0.31	0.13	0.22	0.11	0.28
Indeterminate sex			0.36	0.19	0.22	0.22	0.43	0.42
Renal agenesis			1.78	0.38	0.30	0.22	0.85	1.32
Cystic kidney			1.42	1.11	0.86	0.59	2.62	3.82
Bladder exstrophy			0.71	0.12	0.22	0.15	0.11	0.03
Polydactyly, preaxial			0.71	0.08	0.17	0.67	0.77	0.72
Total Limb reduction defects (include unspecified)			4.62	2.34	2.85	2.56	2.13	2.20
Transverse			2.13	0.92	0.95	0.56	0.59	0.65
Preaxial			0.00	0.00	0.00	0.07	0.00	0.07
Postaxial			0.00	0.00	0.00	0.00	0.00	0.10
Intercalary			0.00	0.00	0.00	0.11	0.06	0.24
Mixed			0.00	0.00	0.00	0.33	0.18	0.44
Unspecified			0.00	0.19	0.73	1.08	1.07	0.65
Diaphragmatic hernia			1.42	1.54	1.38	1.48	1.89	2.68
Omphalocele			2.13	0.58	0.65	0.26	1.87	2.59
Gastroschisis			0.00	0.38	0.56	0.33	3.50	6.54
Unspecified Omphalocele/Gastroschisis			0.71	0.04	0.00	0.00	0.24	0.02
Prune belly sequence			0.00	0.15	0.04	0.00	0.06	0.02
Trisomy 13			0.36	0.54	0.39	0.52	1.06	0.88
Trisomy 18			0.36	0.08	0.39	0.33	1.01	1.84
Down syndrome, all ages (include age unknown)			11.73	7.56	7.41	7.68	10.49	12.29
<20			nr	nr	nr	nr	nr	4.30*
20-24			nr	nr	nr	nr	nr	3.74*
25-29			nr	nr	nr	nr	nr	4.87*
30-34			nr	nr	nr	nr	nr	9.80*
35-39			nr	nr	nr	nr	nr	47.47*
40-44			nr	nr	nr	nr	nr	120.27*
45+			nr	nr	nr	nr	nr	181.82*
unknown			---	---	---	---	---	---

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

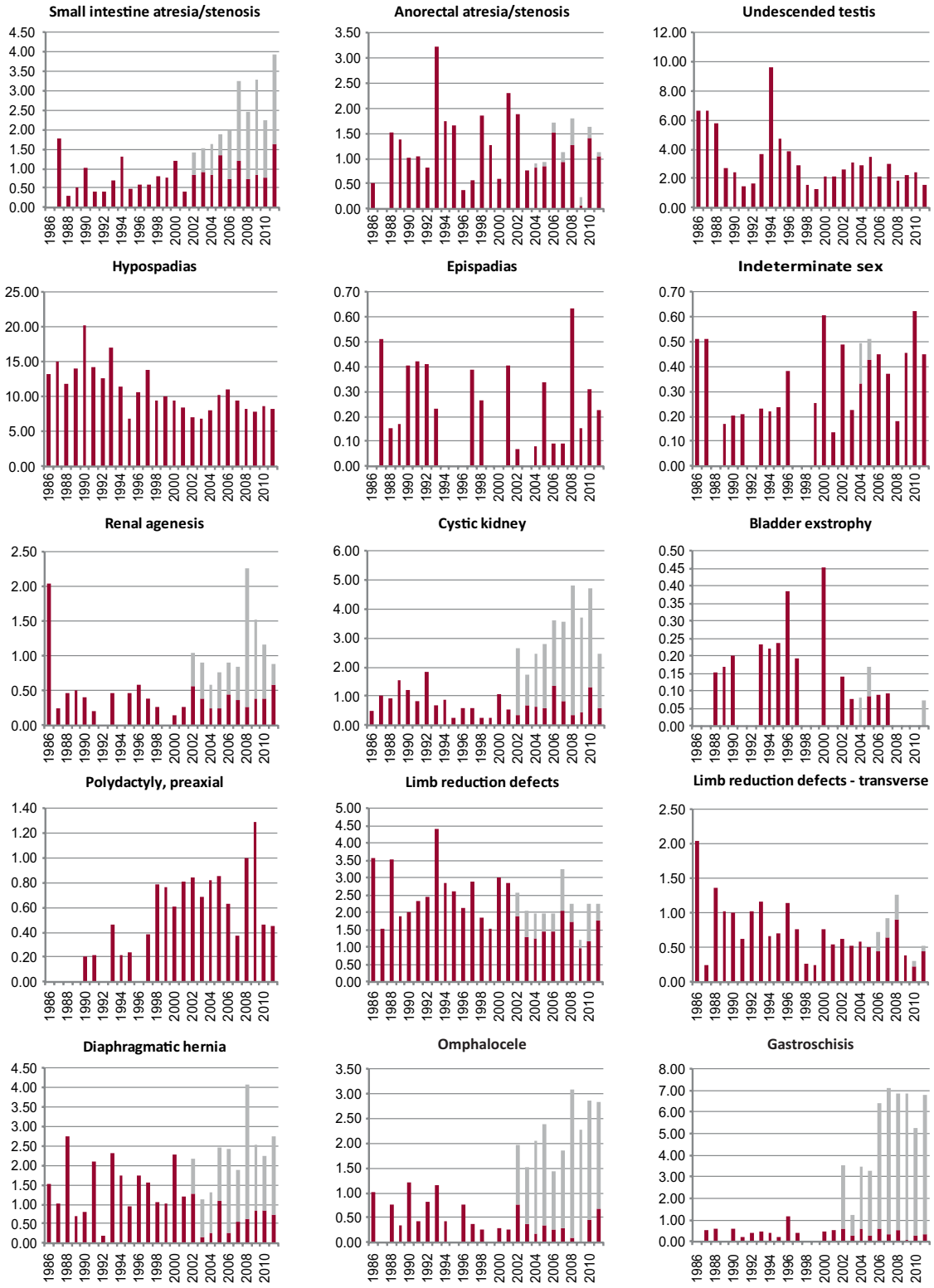
Cuba: RECUMAC

Time trends 1986-2011 (Birth prevalence rates per 10,000)



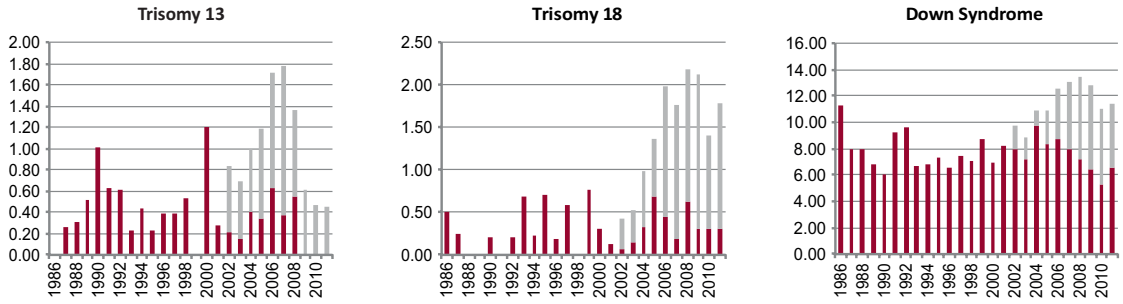
Note: L+S rates, ToP rates

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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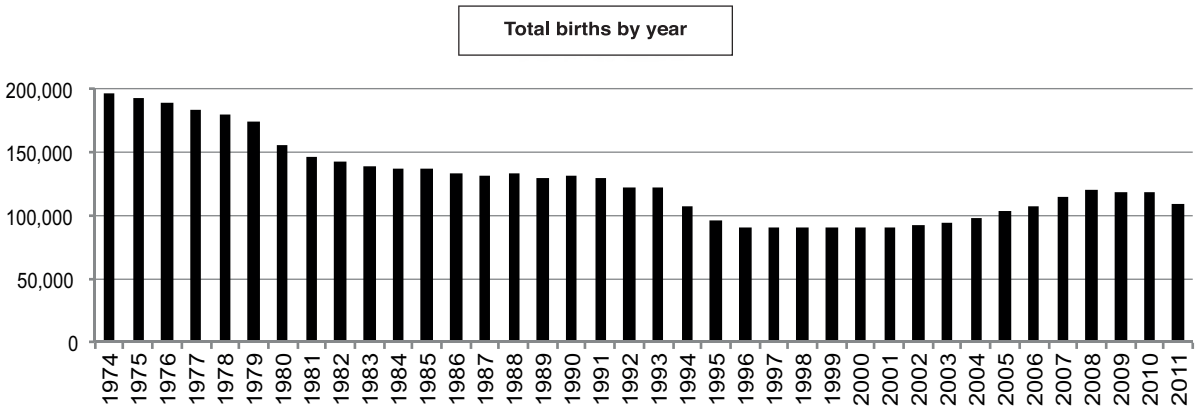
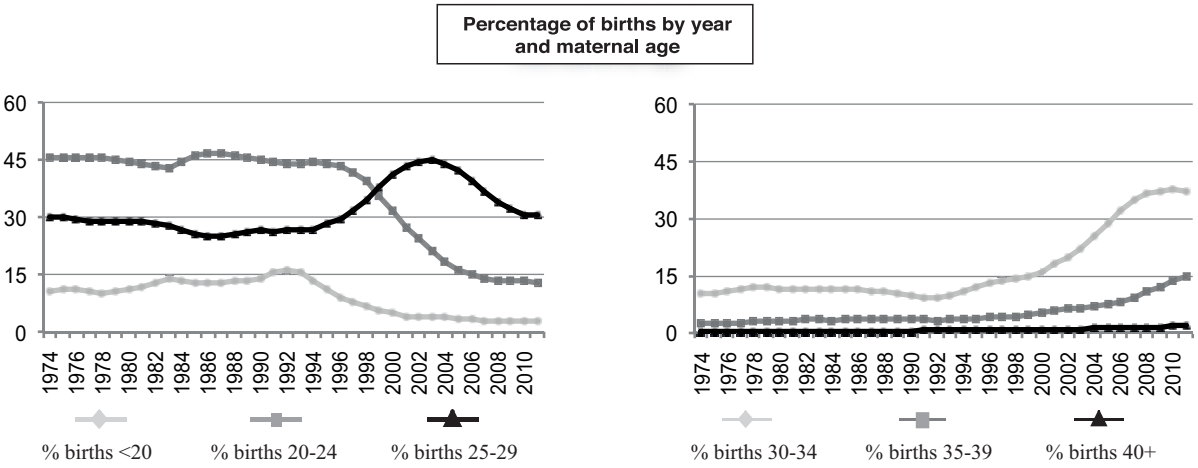
Czech Republic





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	94	96.9	Cystic kidney	22	9.4
Spina bifida	88	67.7	Limb reduction defects	49	19.5
Encephalocele	33	78.6	Diaphragmatic hernia	33	29.2
Holoprosencephaly	18	56.3	Omphalocele	74	62.2
Hydrocephaly	95	59.7	Gastroschisis	78	62.4
Hypoplastic left heart syndrome	107	78.7	Trisomy 13	57	90.5
Cleft palate without cleft lip	3	1.1	Trisomy 18	206	92.0
Cleft lip with or without cleft palate	63	14.5	Down syndrome	656	81.7
Renal agenesis	46	15.0			

Total ToPs with births defects = 2,684 (Ratio ToPs/Births: 7.80 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Czech Republic, 2011

Live births (LB)	107,906
Stillbirths (SB)	250
Total births	108,156
Number of terminations of pregnancy (ToP) for birth defects	848

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	0	33	3.33
Spina bifida	11	1	34	4.25
Encephalocele	1	0	11	1.11
Microcephaly	17	0	2	1.76
Holoprosencephaly	5	1	3	0.83
Hydrocephaly	18	1	26	4.16
Anophthalmos	1	0	0	0.09
Microphthalmos	8	0	0	0.74
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.18
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	31	0	0	2.87
Transposition of great vessels	29	0	24	4.90
Tetralogy of Fallot	37	0	6	3.98
Hypoplastic left heart syndrome	8	1	18	2.50
Coarctation of aorta	62	1	6	6.38
Choanal atresia, bilateral	5	0	0	0.46
Cleft palate without cleft lip	79	0	3	7.58
Cleft lip with or without cleft palate	122	1	17	12.94
Oesophageal atresia/stenosis with or without fistula	46	0	0	4.25
Small intestine atresia/stenosis	45	0	0	4.16
Anorectal atresia/stenosis	38	1	1	3.70
Undescended testis (36 weeks of gestation or later)	373	0	0	34.49
Hypospadias	374	0	0	34.58
Epispadias	12	0	1	1.20
Indeterminate sex	1	0	0	0.09
Renal agenesis	78	0	16	8.69
Cystic kidney	62	0	5	6.19
Bladder exstrophy	7	0	0	0.65
Polydactyly, preaxial	195	1	5	18.58
Total Limb reduction defects (include unspecified)	78	0	19	8.97
Transverse	25	0	2	2.50
Preaxial	1	0	1	0.18
Postaxial	2	0	0	0.18
Intercalary	1	0	0	0.09
Mixed	29	0	3	2.96
Unspecified	20	0	13	3.05
Diaphragmatic hernia	25	0	13	3.51
Omphalocele	17	0	27	4.07
Gastroschisis	16	1	24	3.79
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	1	0	22	2.13
Trisomy 18	8	0	74	7.58
Down syndrome, all ages (include age unknown)	53	0	220	25.24
<20	1	0	1	6.45
20-24	3	0	8	7.87
25-29	6	0	22	8.51
30-34	19	0	67	21.57
35-39	12	0	81	57.62
40-44	10	0	39	233.89
45+	2	0	2	439.56
unknown	0	0	0	---

nr = data not reported or not available

Czech Republic, Previous years rates 1974 - 2011

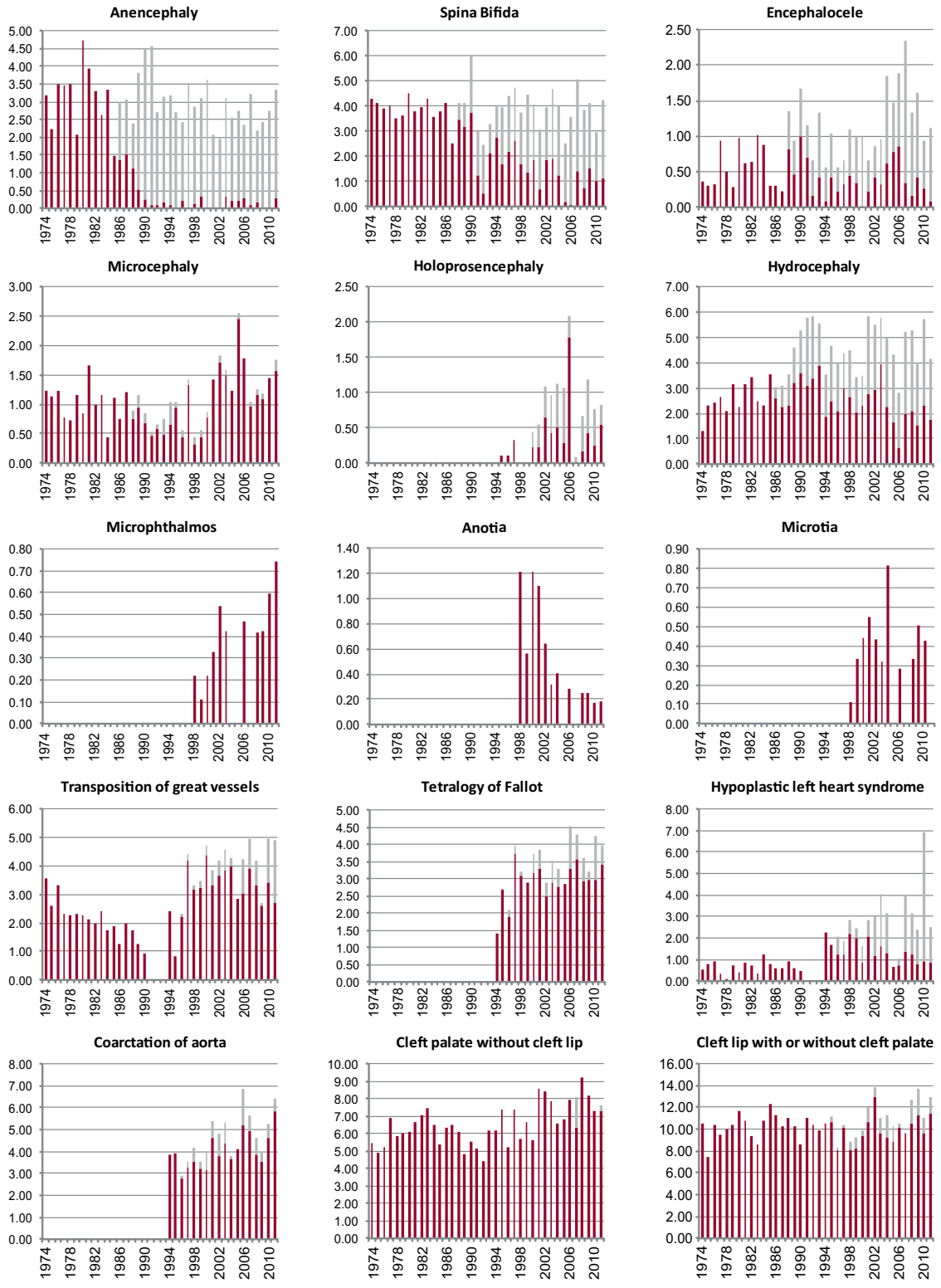
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**576,818**	**835,818**	**688,659**	**654,036**	**536,751**	**453,680**	**493,651**	**579,058**
Anencephaly	2.96	3.49	2.74	3.65	2.85	3.04	2.53	2.76
Spina bifida	4.09	3.88	3.94	3.96	3.56	4.01	3.73	4.04
Encephalocele	0.33	0.66	0.62	1.07	0.84	0.88	1.42	1.47
Microcephaly	1.20	1.01	0.89	0.93	0.80	0.95	1.80	1.33
Holoprosencephaly	nr	nr	nr	nr	0.11*	0.26	1.28	0.71
Hydrocephaly	2.03	2.64	2.96	4.45	4.79	4.34	4.62	4.87
Anophthalmos	nr	nr	nr	nr	nr	0.05*	0.05*	0.32*
Microphthalmos	nr	nr	nr	nr	nr	0.22*	0.36*	0.54*
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	nr	0.00*	0.04	0.15*
Anotia	nr	nr	nr	nr	nr	1.02*	0.41*	0.21*
Microtia	nr	nr	nr	nr	nr	0.36*	0.46*	0.32*
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	7.03*	0.10	0.60
Transposition of great vessels	3.17	2.26	1.86	1.47*	1.87*	3.95	4.01	4.32
Tetralogy of Fallot	nr	nr	nr	nr	2.04*	3.53	3.42	3.85
Hypoplastic left heart syndrome	0.73	0.45	0.74	0.65*	2.01*	2.34	2.33	3.80
Coarctation of aorta	nr	nr	nr	nr	3.57*	4.12	5.00	5.15
Choanal atresia, bilateral	nr	nr	nr	nr	0.31*	0.22	0.33*	0.84*
Cleft palate without cleft lip	5.18	6.28	6.53	5.61	5.83	6.79	7.50	8.08
Cleft lip with or without cleft palate	9.43	10.39	10.47	10.24	10.10	10.10	11.34	12.02
Oesophageal atresia/stenosis with or without fistula	1.18	1.21	1.19	1.01	1.92	2.67	2.94	3.42
Small intestine atresia/stenosis	nr	nr	nr	nr	1.87*	2.38	3.44	3.38
Anorectal atresia/stenosis	1.42	1.24	1.12	0.73	2.40	3.11	3.79	4.18
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	4.76*	16.36	25.18*	33.53*
Hypospadias	19.57	18.15	20.52	23.48	23.88	27.27	32.65	32.05
Epispadias	nr	nr	nr	nr	0.31*	0.53	0.38*	0.50*
Indeterminate sex	nr	nr	nr	nr	0.34*	0.53	0.36*	0.37*
Renal agenesis	1.77	1.52	1.29	1.42	2.29	3.13	7.45	8.39
Cystic kidney	2.36	2.61	2.50	2.80	2.85	4.39	6.00	6.98
Bladder exstrophy	0.12	0.19	0.06	0.02*	0.11*	0.22	0.15*	0.24*
Polydactyly, preaxial	nr	nr	nr	12.28*	13.34	12.19	14.89	15.56
Total Limb reduction defects (include unspecified)	3.80	4.75	5.33	5.17	5.03	5.40	5.85	7.27
Transverse	nr	nr	nr	nr	nr	nr	nr	1.98*
Preaxial	nr	nr	nr	nr	nr	nr	nr	0.19*
Postaxial	nr	nr	nr	nr	nr	nr	nr	0.13*
Intercalary	nr	nr	nr	nr	nr	nr	nr	0.06*
Mixed	nr	nr	nr	nr	nr	nr	nr	1.74*
Unspecified	nr	nr	nr	nr	nr	nr	nr	2.46*
Diaphragmatic hernia	2.51	2.57	2.58	1.85	1.88	2.40	2.92	3.25
Omphalocele	2.22	2.32	2.29	2.43	2.38	2.40	2.39	3.44
Gastroschisis	0.97	1.18	1.38	0.86	1.49	2.95	3.04	3.38
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.02	0.00	0.11*
Prune belly sequence	nr	nr	nr	nr	nr	nr	0.13*	0.17*
Trisomy 13	nr	nr	nr	0.08*	0.71	1.01	2.13	1.90
Trisomy 18	nr	nr	0.45*	0.58	1.96	3.15	4.98	5.63
Down syndrome, all ages (include age unknown)	8.60	8.36	8.20	8.16	12.28	15.45	18.52	22.81
<20	5.69	3.70	5.92	3.52	5.42	8.24	5.88	5.76
20-24	6.32	4.75	4.88	2.95	5.90	8.51	8.86	7.81
25-29	9.58	7.33	8.11	5.16	8.74	10.56	10.19	9.44
30-34	14.85	9.19	8.43	8.24	15.11	20.40	18.42	19.65
35-39	30.92	31.08	31.22	25.62	54.43	56.23	67.63	59.31
40-44	92.63	144.59	77.10	57.84	256.77	212.36	199.57	181.55
45+	79.37	368.10	200.00	404.04	791.37	625.00	504.59	580.47
unknown	---	---	---	---	---	---	---	---

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

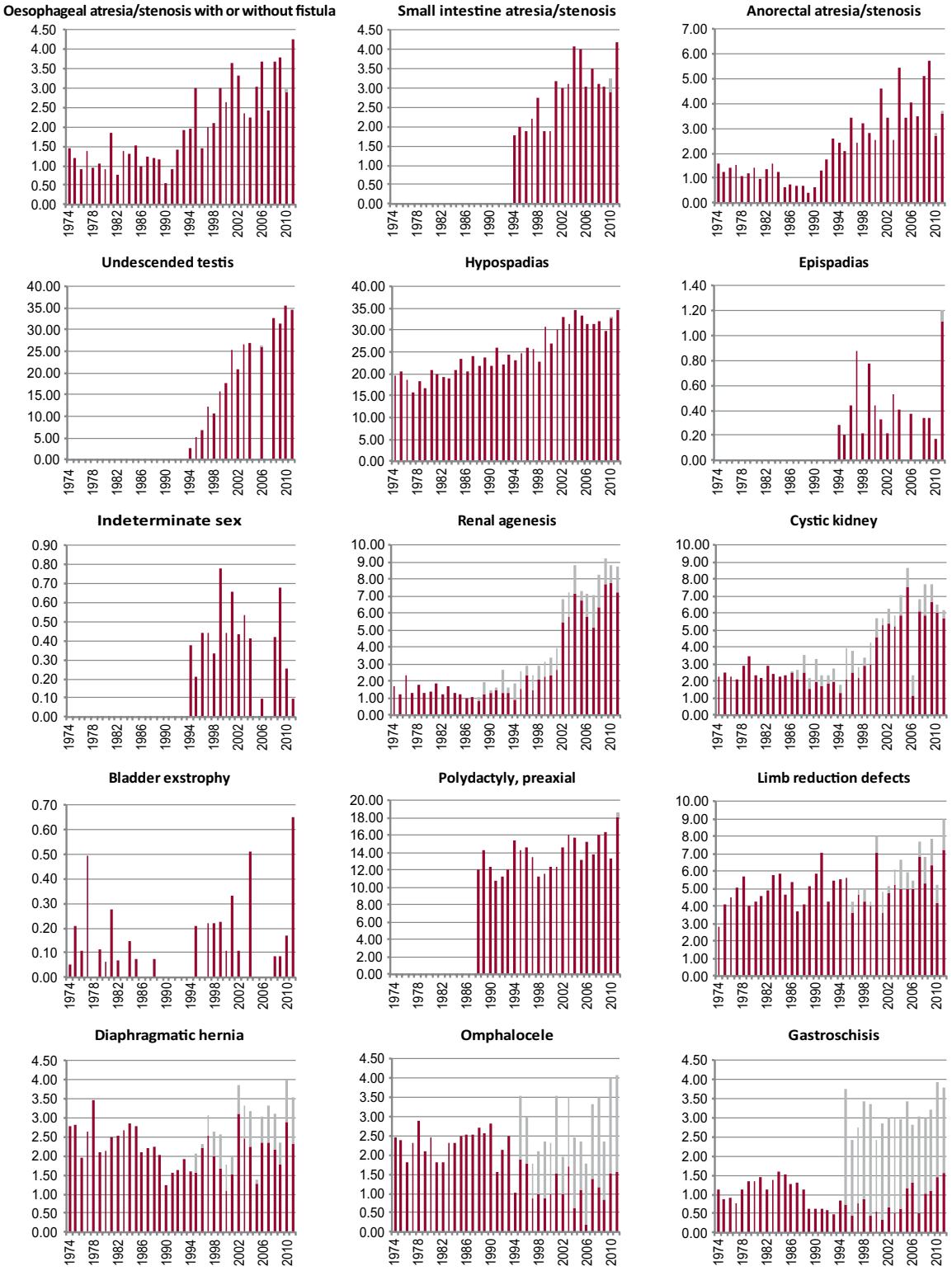
Czech Republic

Time trends 1974-2011 (Birth prevalence rates per 10,000)



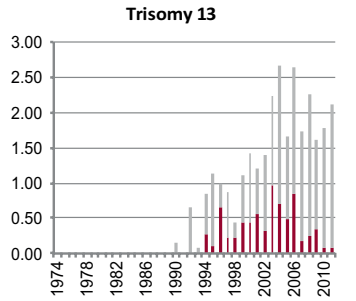
Note: L+S rates, ToP rates

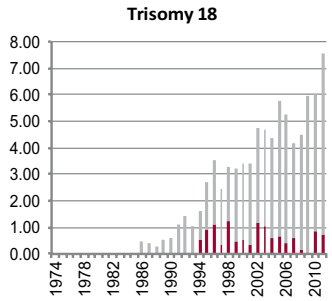
Czech Republic

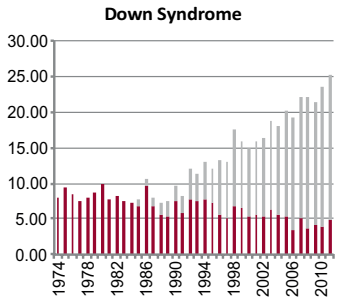


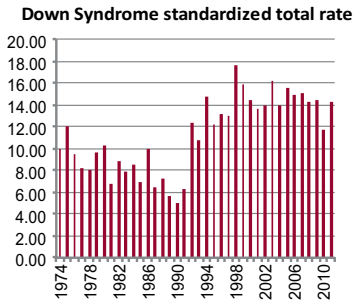
Note: L+S rates, ToP rates

Czech Republic









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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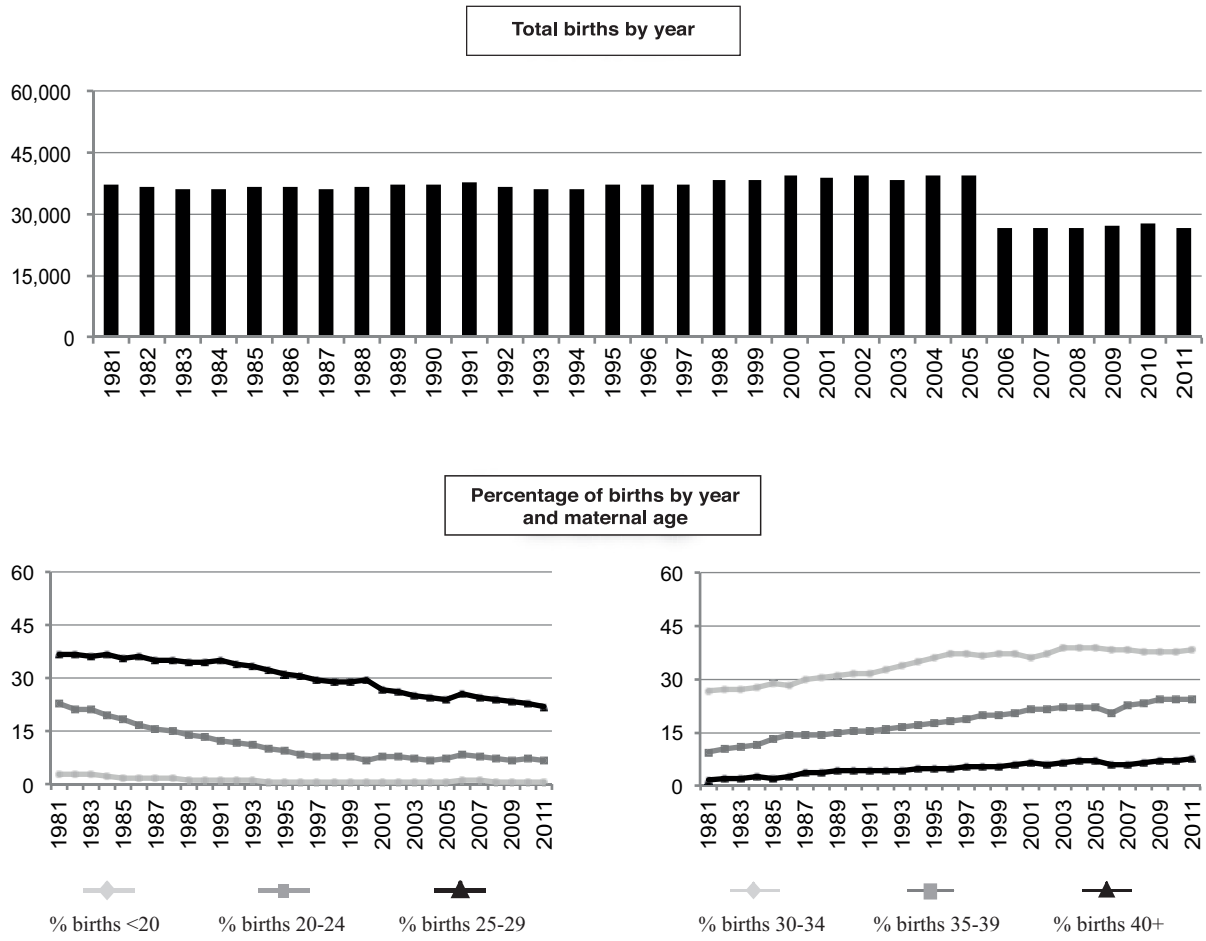


Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	38	95.0	Cystic kidney	20	22.0
Spina bifida	35	85.4	Limb reduction defects	24	42.9
Encephalocele	10	76.9	Diaphragmatic hernia	5	31.3
Holoprosencephaly	12	92.3	Omphalocele	40	74.1
Hydrocephaly	30	30.3	Gastroschisis	4	23.5
Hypoplastic left heart syndrome	17	73.9	Trisomy 13	28	100.0
Cleft palate without cleft lip	10	22.2	Trisomy 18	104	93.7
Cleft lip with or without cleft palate	15	23.8	Down syndrome	278	79.4
Renal agenesis	5	83.3			

Total ToPs with births defects = 845 (Ratio ToPs/Births: 10.4 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Paris, 2011

Live births (LB)	26,093
Stillbirths (SB)	285
Total births	26,378
Number of terminations of pregnancy (ToP) for birth defects	273

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	12	4.93
Spina bifida	3	0	7	3.79
Encephalocele	0	0	4	1.52
Microcephaly	3	1	4	3.03
Holoprosencephaly	0	0	5	1.90
Hydrocephaly	18	0	6	9.10
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	1	1.14
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	1.14
Microtia	1	0	0	0.38
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	3	3.79
Tetralogy of Fallot	6	1	2	3.41
Hypoplastic left heart syndrome	2	0	5	2.65
Coarctation of aorta	6	0	0	2.27
Choanal atresia, bilateral	2	0	0	0.76
Cleft palate without cleft lip	6	0	4	3.79
Cleft lip with or without cleft palate	9	1	4	5.31
Oesophageal atresia/stenosis with or without fistula	5	0	2	2.65
Small intestine atresia/stenosis	2	0	2	1.52
Anorectal atresia/stenosis	7	0	6	4.93
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	61	0	3	24.26
Epispadias	2	0	0	0.76
Indeterminate sex	2	0	1	1.14
Renal agenesis	0	1	2	1.14
Cystic kidney	24	0	8	12.13
Bladder exstrophy	0	0	2	0.76
Polydactyly, preaxial	2	0	2	1.52
Total Limb reduction defects (include unspecified)	12	1	7	7.58
Transverse	8	1	5	5.31
Preaxial	1	0	0	0.38
Postaxial	0	0	0	0.00
Intercalary	0	0	1	0.38
Mixed	3	0	1	1.52
Unspecified	0	0	0	0.00
Diaphragmatic hernia	3	0	3	2.27
Omphalocele	6	0	12	6.82
Gastroschisis	5	0	1	2.27
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	8	3.03
Trisomy 18	2	1	28	11.75
Down syndrome, all ages (include age unknown)	18	3	90	42.08
<20	0	0	1	46.73
20-24	3	0	1	21.75
25-29	1	0	6	12.05
30-34	3	1	26	29.66
35-39	7	1	23	47.92
40-44	4	1	32	208.92
45+	0	0	1	62.11
unknown	0	0	0	---

nr = data not reported or not available

France: Paris, Previous years rates 1981 - 2011

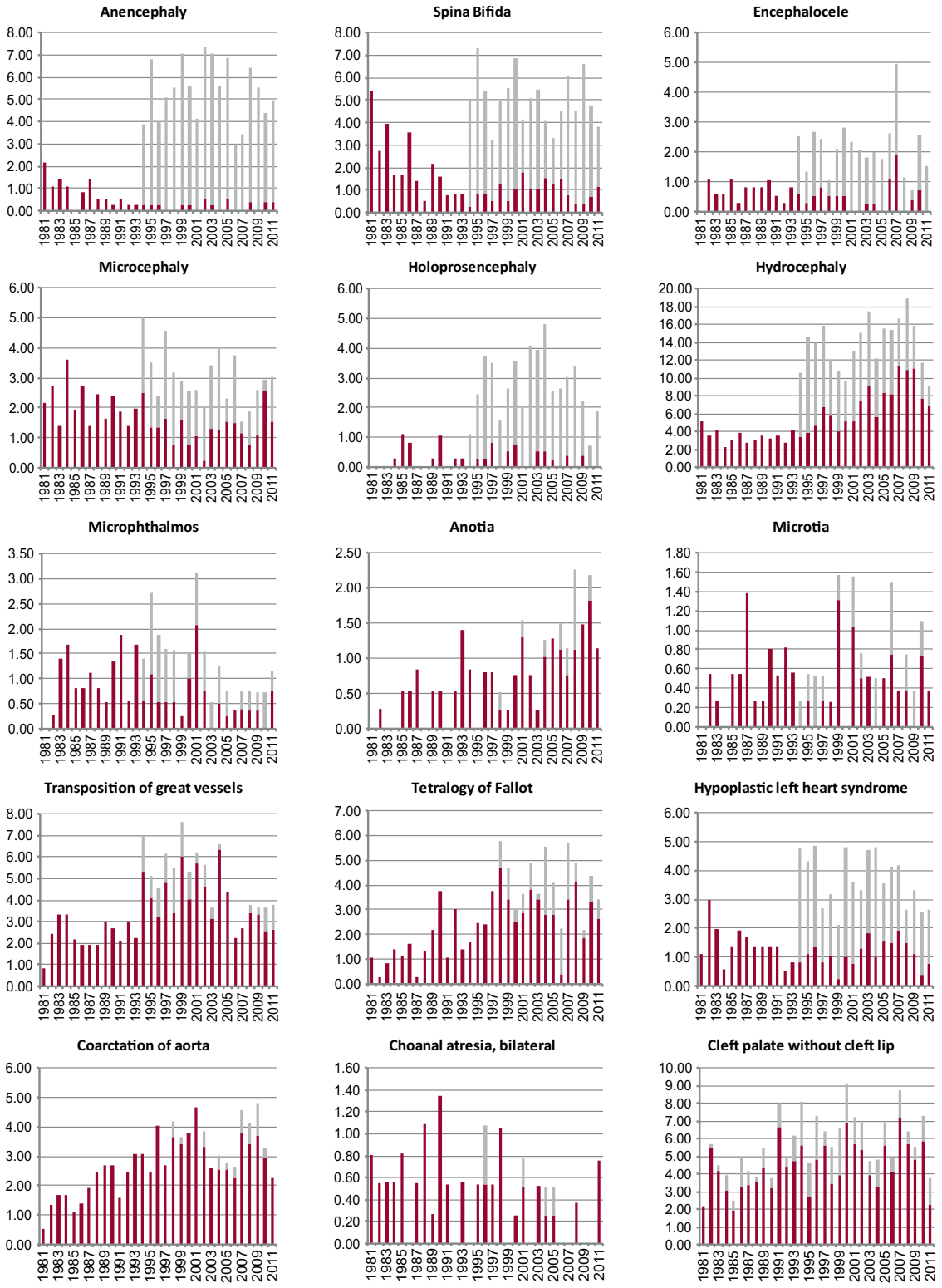
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**36,917**	**181,346**	**184,461**	**182,327**	**191,748**	**183,099**	**133,860**
Anencephaly		2.17	0.88	0.65	3.07	5.48	6.17	4.93
Spina bifida		5.42	2.70	1.30	3.89	4.95	4.48	5.15
Encephalocele		0.00	0.72	0.81	1.54	2.14	2.02	2.17
Microcephaly		2.17	2.48	1.95	2.85	3.13	3.06	2.39
Holoprosencephaly		0.00	0.44	0.27	1.59	2.66	3.66	2.24
Hydrocephaly		5.15	3.36	3.20	9.27	12.20	15.07	14.42
Anophthalmos		0.27	0.22	0.22	0.38	0.31	0.22	0.07
Microphthalmos		0.00	0.99	1.14	1.65	1.62	0.93	0.82
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.00	0.28	0.38	0.71	0.78	0.98	1.64
Microtia		0.00	0.39	0.65	0.55	0.78	0.71	0.60
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		0.81	2.65	2.33	4.39	6.15	4.64	3.51
Tetralogy of Fallot		1.08	1.05	1.73	2.19	4.17	4.21	4.11
Hypoplastic left heart syndrome		1.08	1.76	1.41	3.07	3.29	4.10	3.06
Coarctation of aorta		0.54	1.43	2.28	3.02	3.81	3.00	3.81
Choanal atresia, bilateral		0.81	0.50	0.76	0.44	0.52	0.33	0.22
Cleft palate without cleft lip		2.17	4.30	5.04	6.20	6.99	5.68	6.35
Cleft lip with or without cleft palate		6.23	6.45	8.94	8.99	9.39	7.92	8.22
Oesophageal atresia/stenosis with or without fistula		2.17	2.37	3.58	3.57	3.81	4.04	2.99
Small intestine atresia/stenosis		0.00	0.50	1.41	2.41	2.09	4.26	1.34
Anorectal atresia/stenosis		2.71	3.09	2.11	3.95	3.18	3.50	3.44
Undescended testis (36 weeks of gestation or later)		6.77	10.15	12.69	10.91	5.22	6.63*	nr
Hypospadias		10.29	10.09	12.96	13.05	11.32	16.00	17.26
Epispadias		0.00	0.33	0.60	0.33	0.42	0.44	0.84*
Indeterminate sex		1.90	1.32	1.36	1.26	1.36	1.31	0.97
Renal agenesis		1.08	1.10	0.76	2.63	2.71	2.89	1.20
Cystic kidney		0.81	2.15	3.47	6.80	10.17	10.76	10.76
Bladder exstrophy		0.00	0.39	0.22	0.82	0.47	0.49	0.97
Polydactyly, preaxial		0.27	0.72	1.08	2.03	2.40	1.37	1.87
Total Limb reduction defects (include unspecified)		nr	nr	nr	6.07*	7.56	7.32	6.80
Transverse		nr	nr	nr	1.62*	3.91	4.21	4.18
Preaxial		nr	nr	nr	0.40*	1.36	1.20	1.05
Postaxial		nr	nr	nr	0.40*	0.42	0.87	0.07
Intercalary		nr	nr	nr	0.40*	0.57	0.33	0.52
Mixed		nr	nr	nr	0.13*	0.68	0.44	0.67
Unspecified		nr	nr	nr	0.00*	0.10	0.27	0.30
Diaphragmatic hernia		1.90	2.48	2.82	4.44	5.37	5.30	2.17
Omphalocele		0.81	1.76	2.01	3.24	5.68	5.79	6.42
Gastroschisis		0.00	0.61	1.25	2.58	3.29	2.51	1.72
Unspecified Omphalocele/Gastroschisis		0.00	0.55	0.22	0.55	1.15	0.98	0.37
Prune belly sequence		0.00	0.17	0.05	0.11	0.05	0.27	0.00
Trisomy 13		0.81	0.39	0.60	1.86	3.81	4.64	4.11
Trisomy 18		0.81	1.43	1.19	4.94	9.28	13.60	14.42
Down syndrome, all ages (include age unknown)		10.84	12.02	12.14	25.83	36.56	42.27	42.73
<20		9.03	11.59	10.77	5.81	16.67	12.78	7.66
20-24		10.74	6.22	6.53	10.75	12.14	11.63	14.37
25-29		3.71	7.46	6.82	10.66	14.62	15.08	14.77
30-34		8.12	12.15	12.53	16.06	23.51	23.77	23.46
35-39		17.11	28.49	24.81	48.26	55.22	67.05	58.77
40-44		90.25	31.81	25.14	155.68	203.17	187.15	232.28
45+		810.81	91.74	129.45	243.31	284.55	443.29	151.72
unknown		---	---	---	---	---	---	---

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

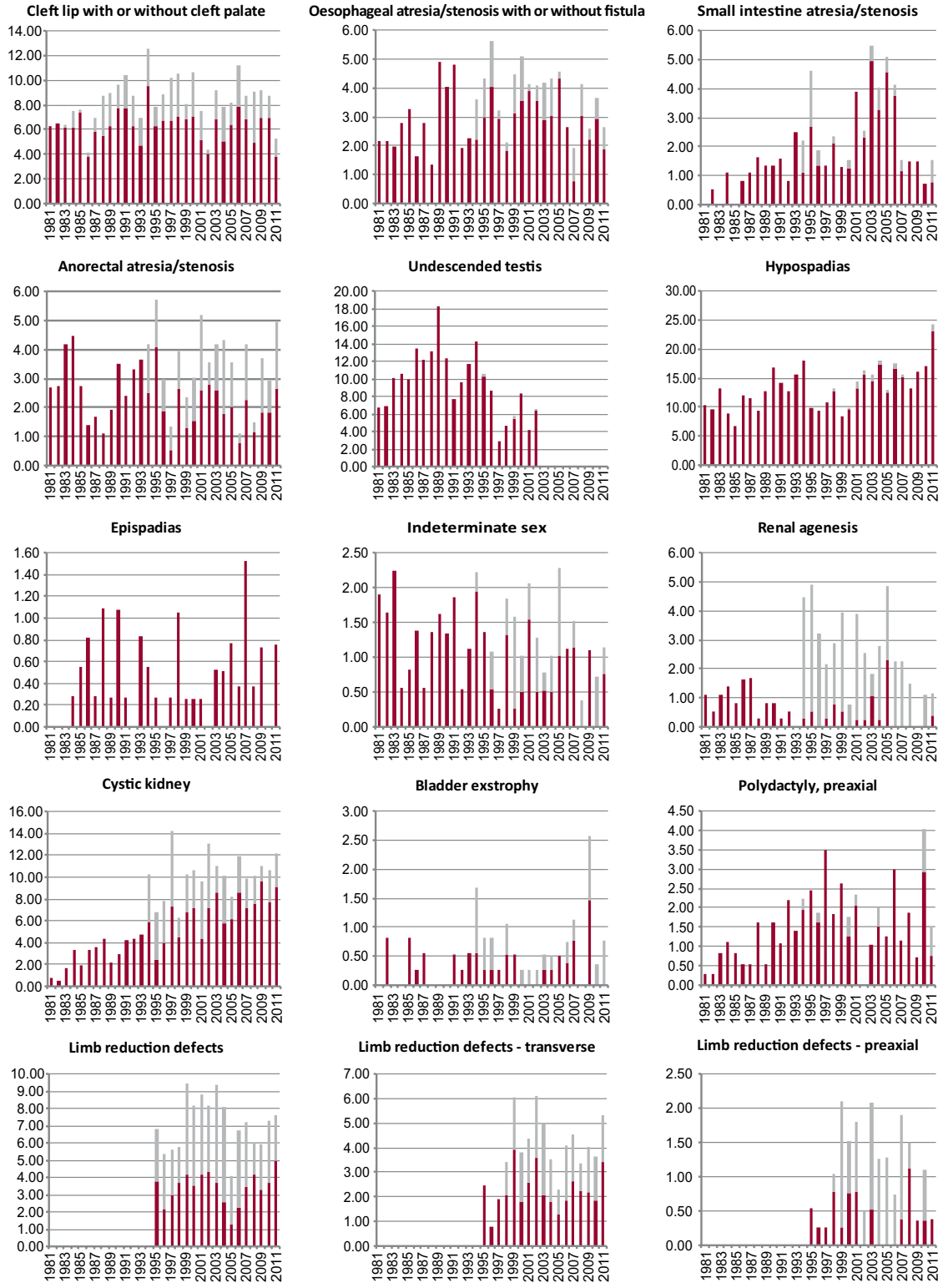
France: Paris

Time trends 1981-2011 (Birth prevalence rates per 10,000)



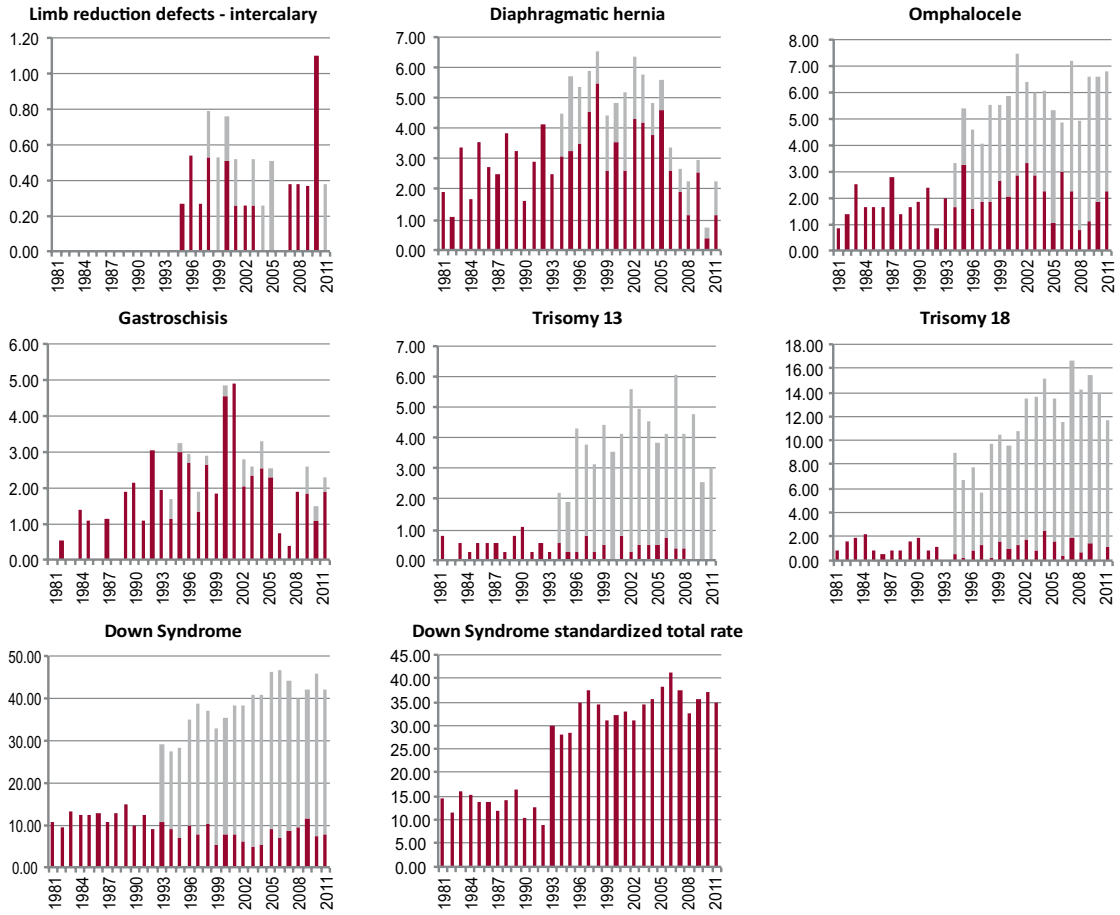
Note: L+S rates, ToP rates

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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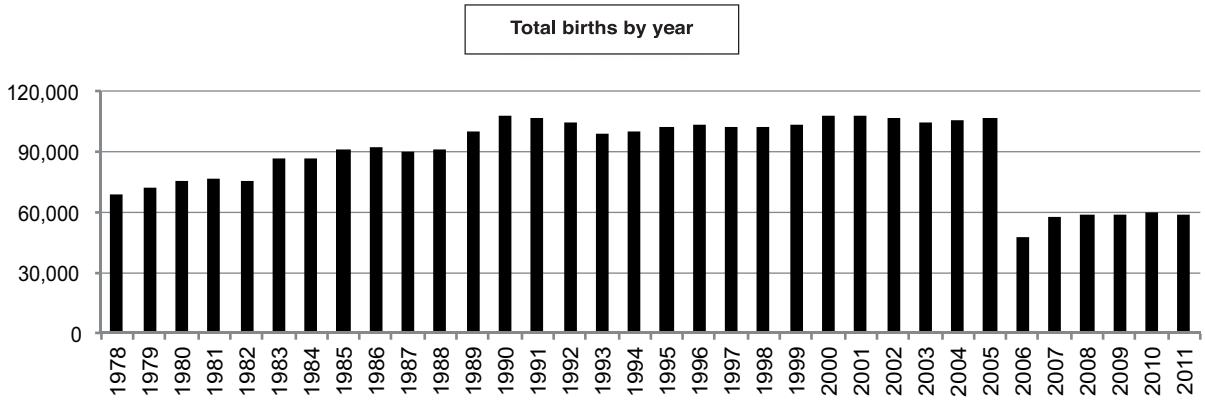
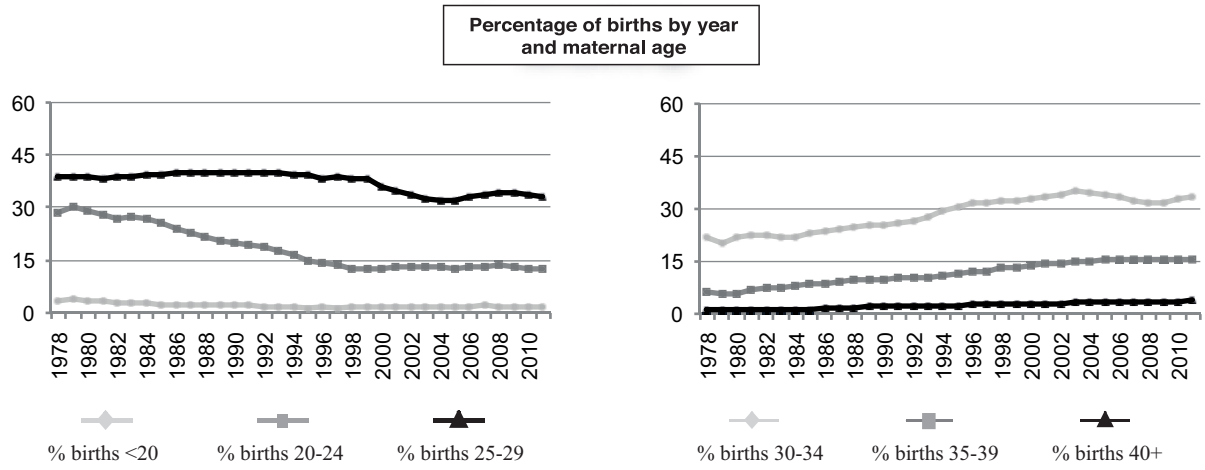




Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	89	96.7	Cystic kidney	73	41.5
Spina bifida	91	87.5	Limb reduction defects	54	55.7
Encephalocele	25	96.2	Diaphragmatic hernia	19	22.4
Holoprosencephaly	35	83.3	Omphalocele	47	68.1
Hydrocephaly	92	60.5	Gastroschisis	8	17.0
Hypoplastic left heart syndrome	57	63.3	Trisomy 13	31	91.2
Cleft palate without cleft lip	21	18.4	Trisomy 18	119	96.7
Cleft lip with or without cleft palate	38	21.2	Down syndrome	380	80.7
Renal agenesis	36	32.7			

Total ToPs with births defects = 1,445 (Ratio ToPs/Births: 8,10 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: REMERA, 2011

Live births (LB)	58,567
Stillbirths (SB)	594
Total births	59,161
Number of terminations of pregnancy (ToP) for birth defects	508

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	38	6.59
Spina bifida	9	1	28	6.42
Encephalocele	0	0	7	1.18
Microcephaly	5	1	3	1.52
Holoprosencephaly	3	0	9	2.03
Hydrocephaly	22	3	38	10.65
Anophthalmos	0	0	0	0.00
Microphthalmos	2	1	3	1.01
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.34
Microtia	6	0	2	1.35
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	24	0	8	5.41
Tetralogy of Fallot	19	1	7	4.56
Hypoplastic left heart syndrome	12	2	21	5.92
Coarctation of aorta	18	0	1	3.21
Choanal atresia, bilateral	7	0	0	1.18
Cleft palate without cleft lip	42	0	7	8.28
Cleft lip with or without cleft palate	52	0	10	10.48
Oesophageal atresia/stenosis with or without fistula	16	2	3	3.55
Small intestine atresia/stenosis	9	0	0	1.52
Anorectal atresia/stenosis	3	0	0	0.51
Undescended testis (36 weeks of gestation or later)	16	1	1	3.04
Hypospadias	82	0	4	14.54
Epispadias	1	0	0	0.17
Indeterminate sex	1	0	0	0.17
Renal agenesis	24	1	14	6.59
Cystic kidney	32	0	22	9.13
Bladder exstrophy	0	0	1	0.17
Polydactyly, preaxial	55	0	9	10.82
Total Limb reduction defects (include unspecified)	11	2	10	3.89
Transverse	7	2	4	2.20
Preaxial	1	0	3	0.68
Postaxial	2	0	1	0.51
Intercalary	0	0	1	0.17
Mixed	1	0	1	0.34
Unspecified	0	0	0	0.00
Diaphragmatic hernia	27	1	6	5.75
Omphalocele	7	0	18	4.23
Gastroschisis	7	1	3	1.86
Unspecified Omphalocele/Gastroschisis	1	0	10	1.86
Prune belly sequence	0	0	2	0.34
Trisomy 13	1	0	10	1.86
Trisomy 18	3	1	46	8.45
Down syndrome, all ages (include age unknown)	37	2	116	26.20
<20	0	0	0	0.00
20-24	5	0	4	11.92
25-29	2	0	9	5.60
30-34	8	1	34	21.93
35-39	7	1	43	54.97
40-44	10	0	23	159.27
45+	1	0	2	256.41
unknown	4	0	1	---

France: REMERA, Previous years rates 1978 - 2011

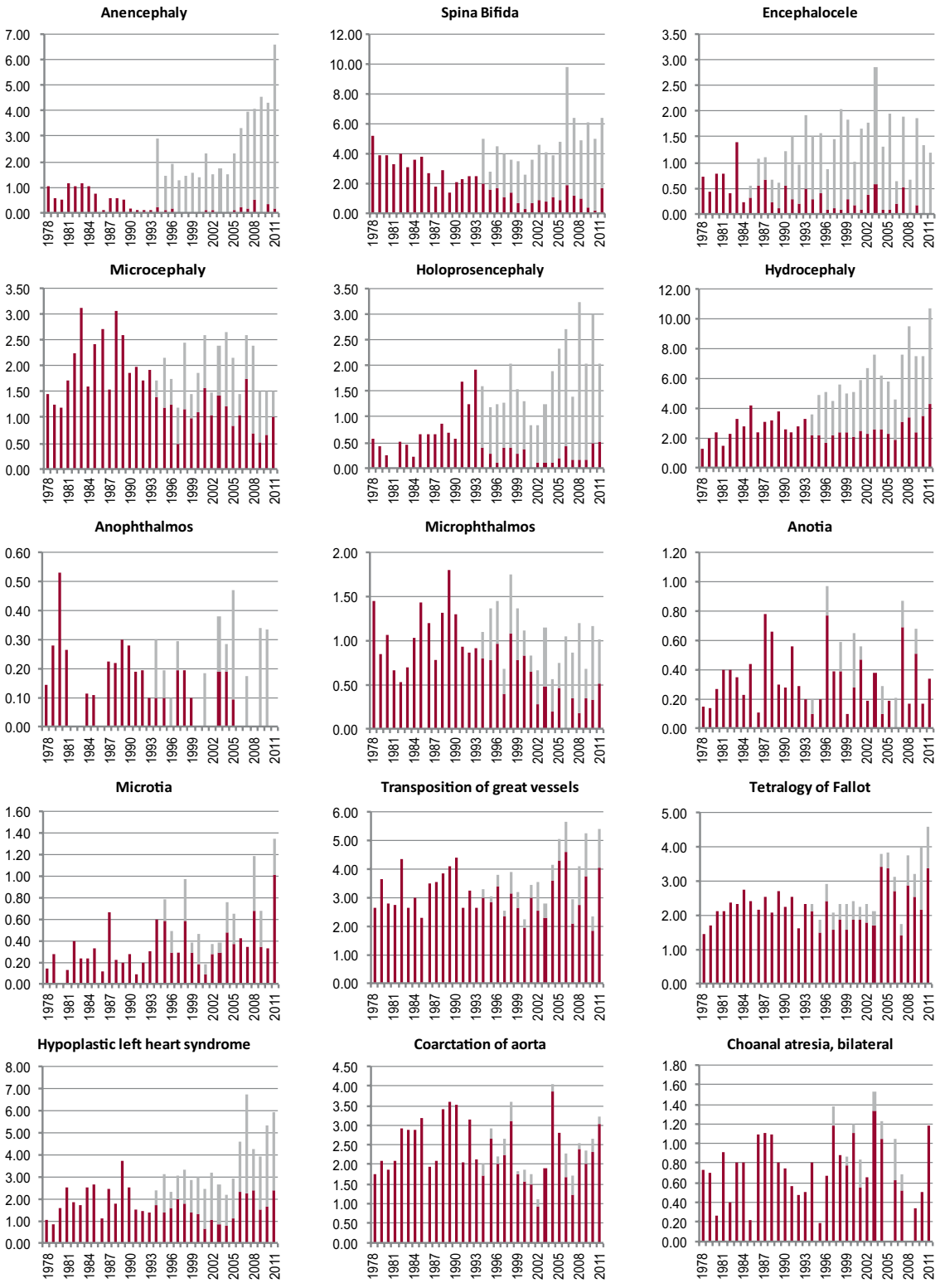
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**291,826**	**431,925**	**495,329**	**508,996**	**523,282**	**472,493**	**294,910**
Anencephaly		0.82	0.81	0.36	1.30	1.61	1.93	4.71
Spina bifida		4.04	3.40	2.06	3.44	3.46	4.89	5.76
Encephalocele		0.69	0.74	1.03	1.36	1.61	1.84	1.39
Microcephaly		1.40	2.43	2.20	1.85	1.91	2.10	1.90
Holoprosencephaly		0.31	0.51	0.91	1.43	1.40	1.69	2.34
Hydrocephaly		1.78	2.99	2.99	3.93	5.20	6.35	8.54
Anophthalmos		0.31	0.05	0.24	0.18	0.15	0.25	0.17
Microphthalmos		0.99	1.00	1.23	1.14	1.15	0.80	0.98
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00	0.30*
Anotia		0.24	0.30	0.50	0.37	0.46	0.25	0.44
Microtia		0.14	0.25	0.28	0.47	0.46	0.53	0.78
Unspecified Anotia/Microtia		0.38	0.56	0.79	0.69	0.92	0.13	0.30*
Transposition of great vessels		2.95	3.13	3.69	3.20	3.06	4.06	4.00
Tetralogy of Fallot		1.85	2.41	2.42	2.20	2.27	3.03	3.46
Hypoplastic left heart syndrome		1.51	1.97	2.38	2.14	2.90	2.92	5.22
Coarctation of aorta		1.95	2.76	2.95	2.50	2.33	2.46	2.51
Choanal atresia, bilateral		0.65	0.67	0.85	0.53	1.03	0.87	0.54
Cleft palate without cleft lip		4.15	5.07	4.64	6.74	6.19	4.99	5.93
Cleft lip with or without cleft palate		6.82	6.11	6.48	8.11	7.59	7.37	9.80
Oesophageal atresia/stenosis with or without fistula		2.02	2.36	3.15	3.06	2.96	2.79	3.39
Small intestine atresia/stenosis		1.64	1.53	1.78	2.02	2.77	2.79	1.53
Anorectal atresia/stenosis		2.09	3.19	3.15	3.71	3.71	3.15	0.27
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	0.00*	1.29
Hypospadias		6.23	6.90	10.20	9.69	12.15	11.94	11.56
Epispadias		0.17	0.19	0.32	0.14	0.29	0.15	0.08*
Indeterminate sex		0.55	0.81	0.77	0.71	0.52	0.80	0.47
Renal agenesis		0.48	0.90	0.46	1.06	1.41	1.78	5.70
Cystic kidney		0.65	1.46	2.73	3.91	4.55	5.21	9.09
Bladder exstrophy		0.17	0.23	0.38	0.33	0.38	0.25	0.47
Polydactyly, preaxial		0.82	0.86	1.59	2.08	2.06	2.20	9.90
Total Limb reduction defects (include unspecified)		4.69	4.07	4.06	4.99	4.97	5.23	5.56
Transverse		2.36	2.06	2.42	2.30	2.56	2.52	2.90*
Preaxial		0.62	0.76	0.52	0.69	0.94	1.23	1.02*
Postaxial		0.31	0.25	0.52	0.26	0.42	0.55	0.60*
Intercalary		0.55	0.49	0.32	0.55	0.40	0.47	0.25*
Mixed		0.62	0.49	0.26	0.29	0.36	0.42	0.25*
Unspecified		0.24	0.02	0.00	0.06	0.08	0.05*	0.17*
Diaphragmatic hernia		1.92	2.80	2.28	3.20	2.58	3.32	4.20
Omphalocele		1.06	1.09	1.27	1.69	2.54	2.62	3.66
Gastroschisis		0.55	0.74	1.03	1.20	1.26	1.74	2.37
Unspecified Omphalocele/Gastroschisis		0.00	0.00	0.00	0.04	0.08	0.08*	2.41
Prune belly sequence		0.27	0.16	0.38	0.47	0.40	0.17	0.31
Trisomy 13		0.41	0.58	1.09	1.14	1.93	2.35	2.37
Trisomy 18		0.89	1.02	2.30	3.14	4.64	4.53	7.15
Down syndrome, all ages (include age unknown)		11.38	11.11	10.96	16.70	20.51	23.41	26.41
<20		7.79	3.32	7.46	4.94	11.56	6.75	3.95
20-24		6.47	6.40	5.74	7.33	7.97	7.83	8.31
25-29		5.59	5.95	6.60	6.80	7.88	8.31	8.10
30-34		11.80	10.23	9.05	10.74	14.30	14.53	20.99
35-39		26.78	29.09	22.03	39.30	45.07	49.31	58.19
40-44		102.73	60.73	51.43	125.36	142.63	149.30	161.67
45+		91.46	109.89	127.93	358.31	203.76	238.41	294.74
unknown		---	---	---	---	---	---	---

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

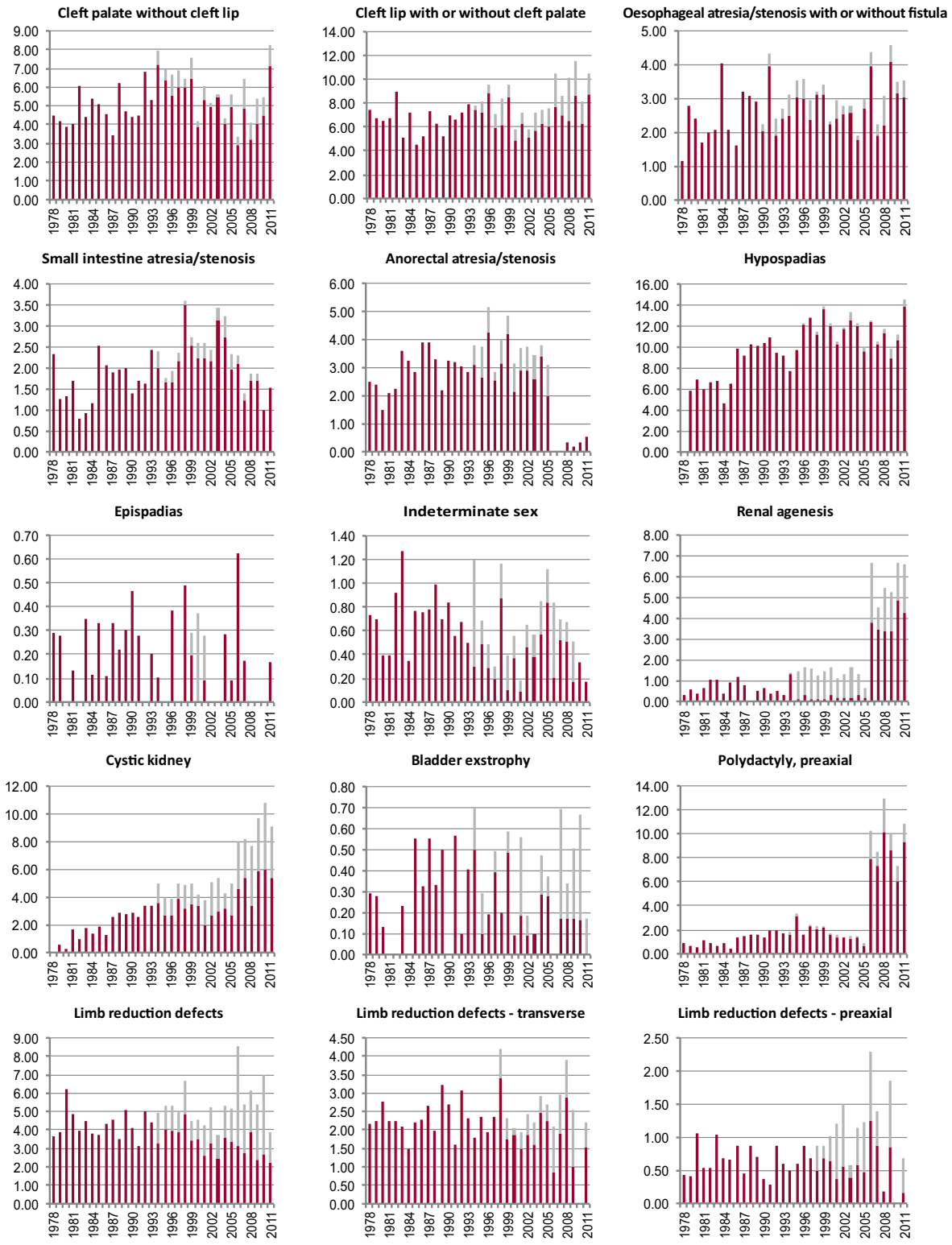
France: REMERA

Time trends 1978-2011 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

France: REMERA



Note: L+S rates, ToP rates

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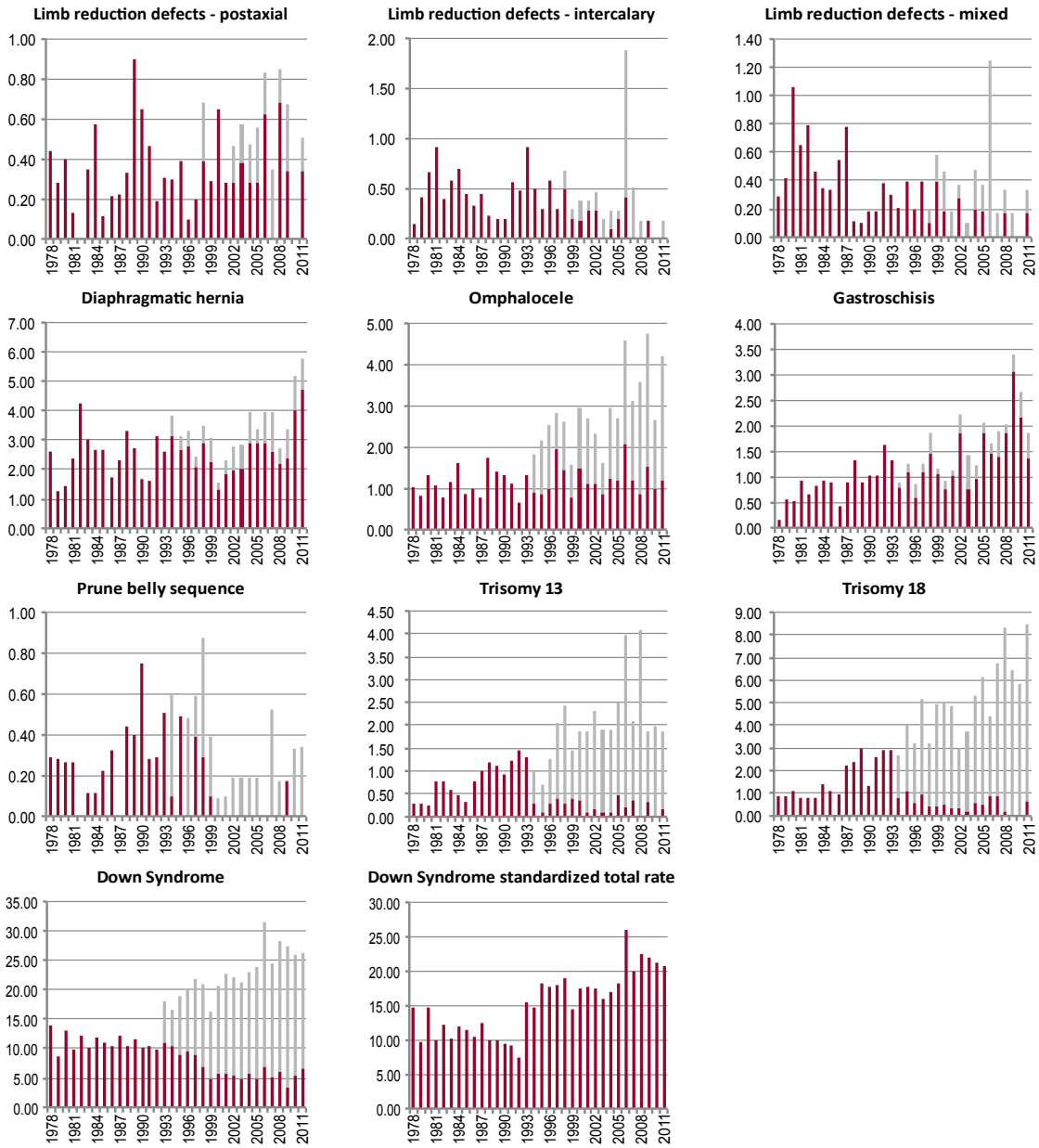

Note: L+S rates, ToP rates

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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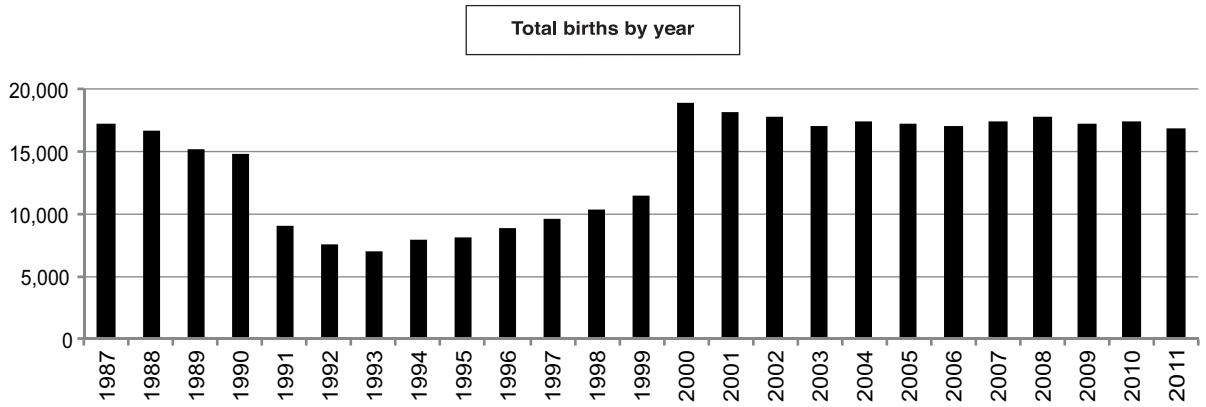
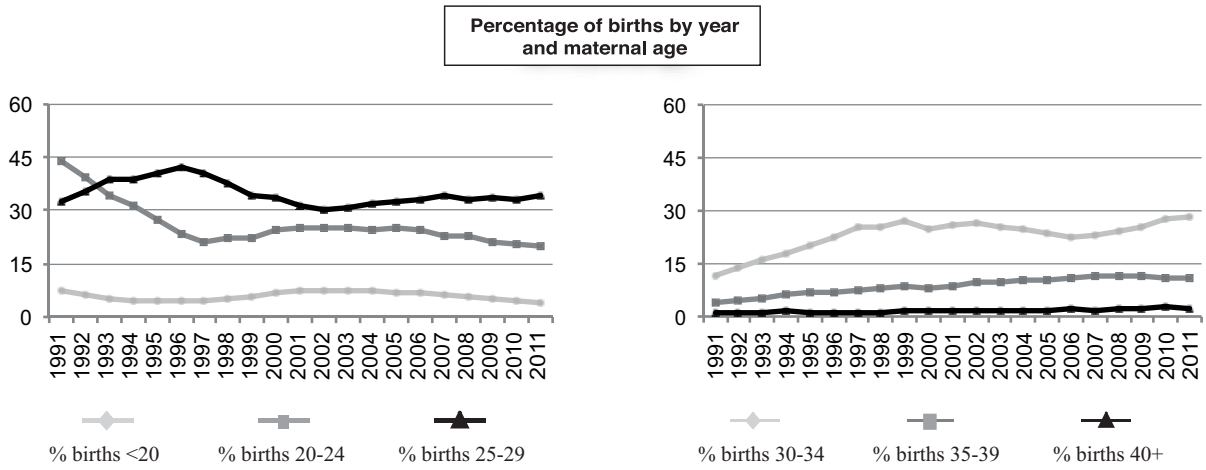
Germany: Saxony Anhalt





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	5	100.0	Cystic kidney	6	12.0
Spina bifida	13	59.1	Limb reduction defects	11	33.3
Encephalocele	4	66.7	Diaphragmatic hernia	3	23.1
Holoprosencephaly	11	84.6	Omphalocele	8	57.1
Hydrocephaly	7	28.0	Gastroschisis	3	15.8
Hypoplastic left heart syndrome	2	20.0	Trisomy 13	6	100.0
Cleft palate without cleft lip	3	11.5	Trisomy 18	20	83.3
Cleft lip with or without cleft palate	10	16.7	Down syndrome	54	60.7
Renal agenesis	4	26.7			

Total ToPs with births defects = 272 (Ratio ToPs/Births: 5.28 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Germany: Saxony-Anhalt, 2011

Live births (LB)	16,837
Stillbirths (SB)	69
Total births	16,906
Number of terminations of pregnancy (ToP) for birth defects	88

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	1	0.59
Spina bifida	2	0	0	1.18
Encephalocele	0	0	3	1.77
Microcephaly	13	5	0	10.65
Holoprosencephaly	1	0	1	1.18
Hydrocephaly	8	0	1	5.32
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.59
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.59
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	10	0	0	5.92
Tetralogy of Fallot	2	0	0	1.18
Hypoplastic left heart syndrome	2	0	2	2.37
Coarctation of aorta	8	0	0	4.73
Choanal atresia, bilateral	1	0	0	0.59
Cleft palate without cleft lip	7	0	2	5.32
Cleft lip with or without cleft palate	15	1	3	11.24
Oesophageal atresia/stenosis with or without fistula	3	1	0	2.37
Small intestine atresia/stenosis	3	0	0	1.77
Anorectal atresia/stenosis	7	0	2	5.32
Undescended testis (36 weeks of gestation or later)	7	0	0	4.14
Hypospadias	16	0	0	9.46
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	1	1	2	2.37
Cystic kidney	14	0	2	9.46
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	6	0	0	3.55
Total Limb reduction defects (include unspecified)	10	0	4	8.28
Transverse	5	0	0	2.96
Preaxial	1	0	1	1.18
Postaxial	0	0	0	0.00
Intercalary	1	0	1	1.18
Mixed	3	0	1	2.37
Unspecified	0	0	1	0.59
Diaphragmatic hernia	2	0	1	1.77
Omphalocele	3	0	3	3.55
Gastroschisis	6	1	1	4.73
Unspecified Omphalocele/Gastroschisis	6	1	1	4.73
Prune belly sequence	2	1	2	2.96
Trisomy 13	0	0	2	1.18
Trisomy 18	1	1	4	3.55
Down syndrome, all ages (include age unknown)	10	0	18	16.56
<20	0	0	0	0.00
20-24	0	0	0	0.00
25-29	4	0	2	10.32
30-34	4	0	8	25.39
35-39	1	0	4	26.58
40-44	1	0	3	99.75
45+	0	0	1	500.00
unknown	0	0	0	---

Germany: Saxony-Anhalt, Previous years rates 1980 - 2011

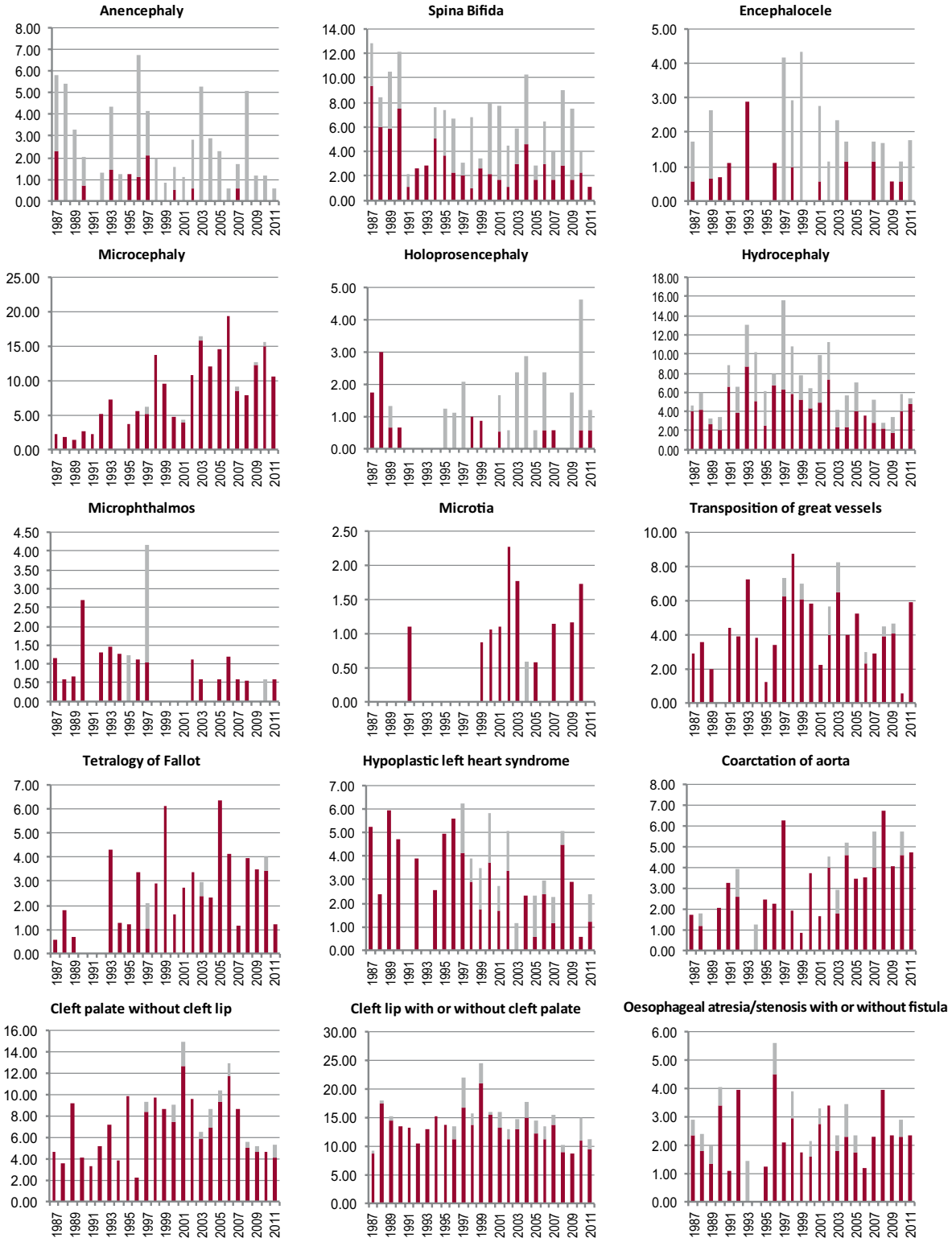
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**35,995**	**86,498**	**72,876**	**39,442**	**68,295**	**86,294**	**86,715**
Anencephaly		1.11	2.20	3.70	3.04	1.76	2.78	1.96
Spina bifida		3.06	6.82	9.88	5.58	6.30	6.03	5.19
Encephalocele		0.28	0.81	1.23	0.76	2.49	1.04	1.38
Microcephaly		nr	nr	2.06	4.31	7.03	14.60	11.19
Holoprosencephaly		nr	nr	1.51	0.51	1.02	1.74	1.61
Hydrocephaly		nr	nr	4.94	8.62	9.52	6.37	4.50
Anophthalmos		nr	nr	0.00	1.01	0.15	0.23	0.35
Microphthalmos		nr	nr	1.10	1.27	0.59	0.70	0.46
Unspecified Anophthalmos/Microphthalmos		nr	nr	0.00	0.00	0.00	0.00	0.00
Anotia		nr	nr	0.00	0.25	0.15	0.23	0.46
Microtia		nr	nr	0.14	0.00	0.73	1.04	0.81
Unspecified Anotia/Microtia		nr	nr	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		nr	nr	2.47	3.80	5.71	5.21	3.69
Tetralogy of Fallot		nr	nr	0.69	2.03	2.93	3.82	2.77
Hypoplastic left heart syndrome		nr	nr	3.98	3.55	4.39	2.78	2.65
Coarctation of aorta		nr	nr	1.65	2.03	2.78	3.94	5.42
Choanal atresia, bilateral		nr	nr	0.96	1.27	0.88	0.46	0.46
Cleft palate without cleft lip		nr	nr	5.08	5.58	10.69	9.62	5.88
Cleft lip with or without cleft palate		nr	nr	13.86	13.18	18.16	14.72	12.11
Oesophageal atresia/stenosis with or without fistula		nr	nr	2.61	2.54	2.64	2.55	2.77
Small intestine atresia/stenosis		nr	nr	1.51	2.79	1.76	2.20	1.38
Anorectal atresia/stenosis		nr	nr	3.84	2.54	2.64	3.71	6.92
Undescended testis (36 weeks of gestation or later)		nr	nr	12.35	17.24	10.84	11.59	4.50
Hypospadias		nr	nr	13.31	21.04	13.03	8.92	7.15
Epispadias		nr	nr	0.27	0.76	0.29	0.35	0.46
Indeterminate sex		nr	nr	0.41	0.00	1.17	0.58	0.23
Renal agenesis		nr	nr	1.51	1.27	2.64	2.09	2.42
Cystic kidney		nr	nr	1.92	4.56	3.66	8.11	8.65
Bladder exstrophy		nr	nr	0.69	0.76	0.00	0.23	0.12
Polydactyly, preaxial		nr	nr	0.41	3.04	4.83	2.67	5.54
Total Limb reduction defects (include unspecified)		nr	nr	5.63	5.83	8.93	6.49	7.73
Transverse		nr	nr	nr	nr	3.52*	2.43	1.73
Preaxial		nr	nr	nr	nr	0.27*	0.46	1.50
Postaxial		nr	nr	nr	nr	0.00*	0.00	0.58
Intercalary		nr	nr	nr	nr	2.71*	0.93	0.23
Mixed		nr	nr	nr	nr	1.62*	1.85	2.88
Unspecified		nr	nr	nr	nr	0.00*	0.81	0.81
Diaphragmatic hernia		nr	nr	1.92	0.00	1.90	2.90	2.88
Omphalocele		nr	nr	4.80	1.77	2.93	3.94	2.65
Gastroschisis		nr	nr	1.51	2.79	3.07	4.87	3.46
Unspecified Omphalocele/Gastroschisis		nr	nr	nr	nr	0.27*	0.00	1.15
Prune belly sequence		nr	nr	0.27	0.76	1.02	0.81	0.92
Trisomy 13		0.00	0.35	0.55	0.76	1.90	1.04	1.04
Trisomy 18		0.28	1.16	0.96	1.27	1.90	3.71	4.38
Down syndrome, all ages (include age unknown)		7.22	9.13	9.06	12.17	17.42	15.64	17.07
<20		nr	nr	nr	nr	3.71*	4.88	0.00
20-24		nr	nr	nr	nr	6.60*	7.50	6.45
25-29		nr	nr	nr	nr	11.62*	7.32	7.54
30-34		nr	nr	nr	nr	11.73*	13.76	17.50
35-39		nr	nr	nr	nr	71.73*	43.95	45.09
40-44		nr	nr	nr	nr	119.28*	178.19	137.20
45+		nr	nr	nr	nr	526.32*	344.83	487.80
unknown		---	---	---	---	---	---	---

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

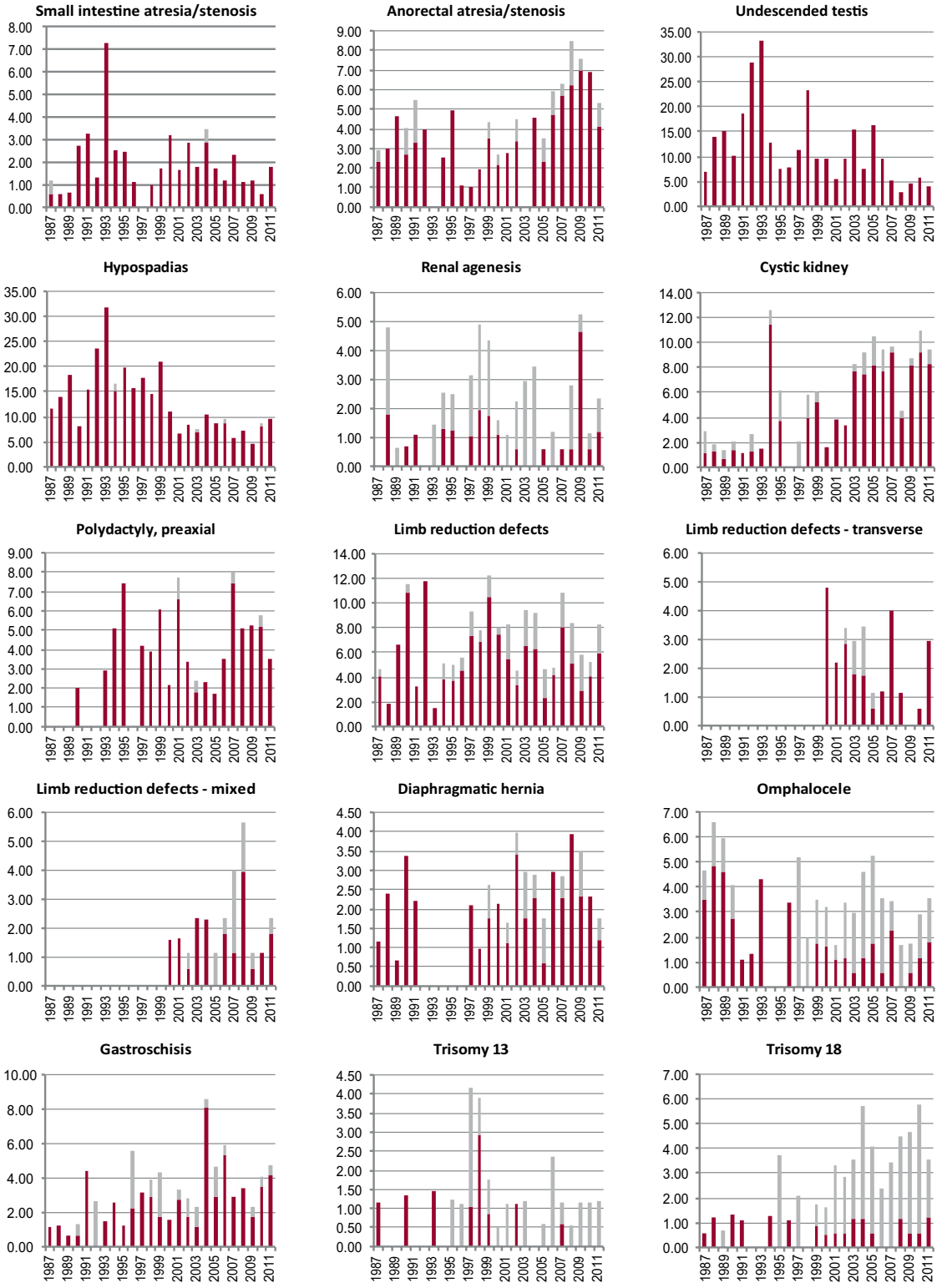
Germany: Saxony-Anhalt

Time trends 1987-2011 (Birth prevalence rates per 10,000)



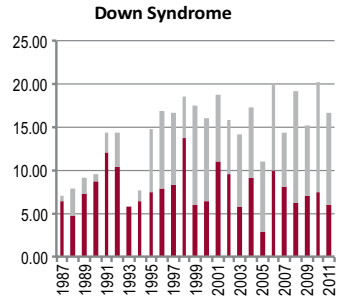
Note: L+S rates, ToP rates

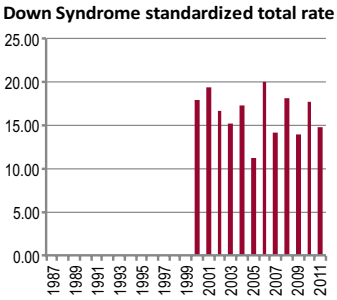
Germany: Saxony-Anhalt



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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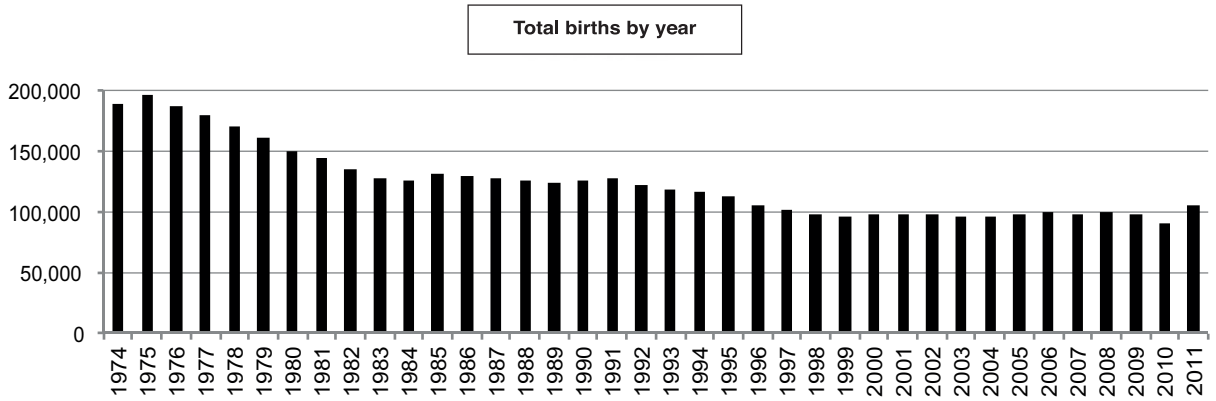
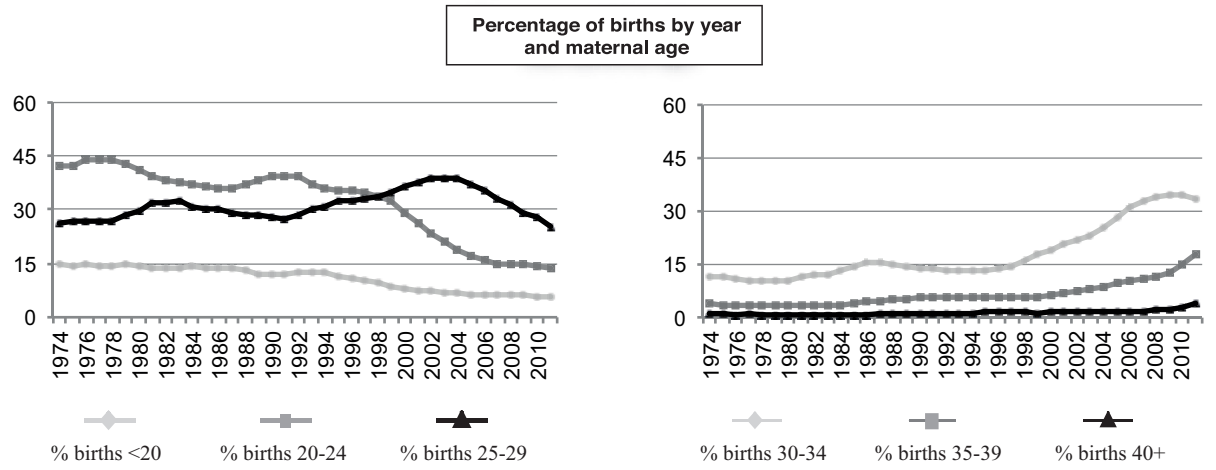
Hungary





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	34	91.9	Cystic kidney	24	21.8
Spina bifida	64	63.4	Limb reduction defects	18	18.9
Encephalocele	22	78.6	Diaphragmatic hernia	16	21.9
Holoprosencephaly	12	57.1	Omphalocele	26	55.3
Hydrocephaly	58	40.6	Gastroschisis	20	64.5
Hypoplastic left heart syndrome	16	28.1	Trisomy 13	26	70.3
Cleft palate without cleft lip	11	7.2	Trisomy 18	87	84.5
Cleft lip with or without cleft palate	26	12.1	Down syndrome	368	62.1
Renal agenesis	6	16.7			

Total ToPs with births defects = 897 (Ratio ToPs/Births: 3.06 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Hungary, 2011

Live births (LB)	88,049
Stillbirths (SB)	17,220
Total births	105,269
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	0	8	0.85
Spina bifida	9	0	19	2.66
Encephalocele	1	0	7	0.76
Microcephaly	9	0	2	1.04
Holoprosencephaly	1	0	1	0.19
Hydrocephaly	10	2	13	2.37
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	1	0	0	0.09
Anotia	3	0	0	0.28
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	22	0	1	2.18
Tetralogy of Fallot	41	0	0	3.89
Hypoplastic left heart syndrome	8	0	6	1.33
Coarctation of aorta	25	0	0	2.37
Choanal atresia, bilateral	18	0	0	1.71
Cleft palate without cleft lip	30	0	5	3.32
Cleft lip with or without cleft palate	41	0	6	4.46
Oesophageal atresia/stenosis with or without fistula	18	0	0	1.71
Small intestine atresia/stenosis	11	0	4	1.42
Anorectal atresia/stenosis	15	0	0	1.42
Undescended testis (36 weeks of gestation or later)	161	0	0	15.29
Hypospadias	191	0	0	18.14
Epispadias	36	0	6	3.99
Indeterminate sex	0	0	0	0.00
Renal agenesis	27	0	2	2.75
Cystic kidney	28	0	4	3.04
Bladder exstrophy	4	0	0	0.38
Polydactyly, preaxial	11	0	0	1.04
Total Limb reduction defects (include unspecified)	16	0	4	1.90
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	9	0	5	1.33
Omphalocele	5	0	9	1.33
Gastroschisis	6	0	8	1.33
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.09
Trisomy 13	4	0	2	0.57
Trisomy 18	3	0	31	3.23
Down syndrome, all ages (include age unknown)	71	0	131	19.19
<20	8	0	3	18.30
20-24	1	0	4	3.53
25-29	11	0	11	8.23
30-34	18	0	24	11.97
35-39	23	0	59	43.60
40-44	5	0	29	80.21
45+	2	0	1	133.93
unknown	3	0	0	---

nr = data not reported or not available

Hungary, Previous years rates 1974 - 2011

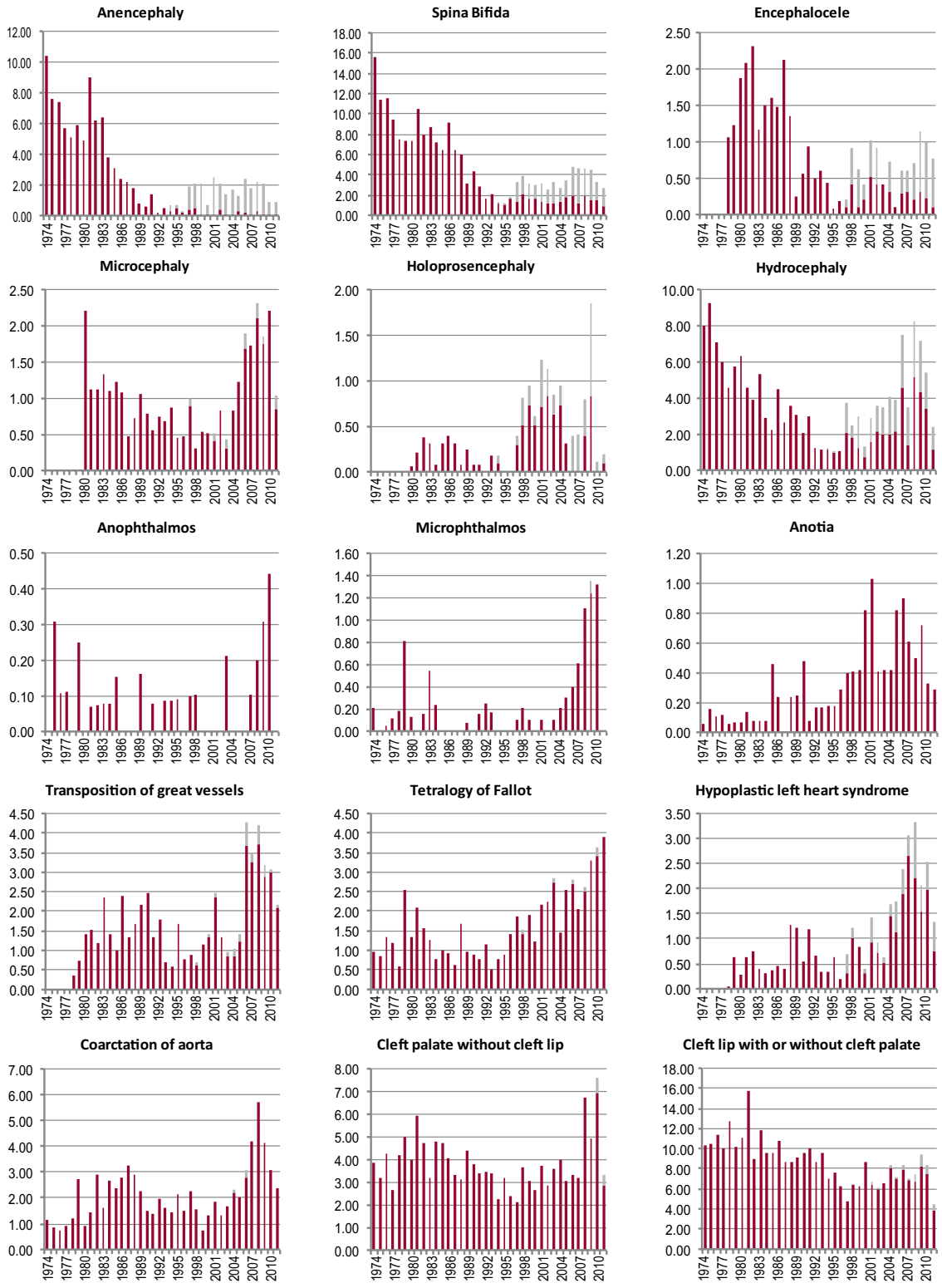
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**570,720**	**804,244**	**648,937**	**629,899**	**573,813**	**489,535**	**486,479**	**490,630**
Anencephaly	8.45	6.06	4.41	1.37	0.47	1.84	1.77	1.57
Spina bifida	12.86	8.42	7.87	4.52	1.59	3.29	3.37	3.93
Encephalocele	nr	1.54*	1.62	1.05	0.37	0.63	0.56	0.84
Microcephaly	nr	1.67*	1.17	0.71	0.64	0.57	1.05	1.81
Holoprosencephaly	nr	0.14*	0.29	0.16	0.07	0.80	0.72	0.67
Hydrocephaly	8.13	5.46	3.76	2.87	1.13	2.68	4.52	5.28
Anophthalmos	0.14	0.09	0.08	0.05	0.05	0.04	0.04	0.20
Microphthalmos	0.09	0.25	0.18	0.05	0.09	0.10	0.21	0.86
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	nr	nr	nr	0.09*
Anotia	0.11	0.09	0.18	0.21	0.19	0.61	0.60	0.49
Microtia	0.04	0.05	0.02	0.02	0.03	0.04	0.12	0.10
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr	0.00*
Transposition of great vessels	nr	0.98*	1.66	1.79	1.12	1.33	1.83	3.22
Tetralogy of Fallot	1.05	1.52	1.11	0.98	0.94	1.74	2.38	3.10
Hypoplastic left heart syndrome	nr	0.38*	0.46	0.92	0.44	0.92	1.48	2.45
Coarctation of aorta	0.93	1.43	2.48	2.25	1.74	1.55	2.10	3.89
Choanal atresia, bilateral	nr	0.20*	0.09	0.21	0.09	0.02	0.14	1.12
Cleft palate without cleft lip	3.77	4.28	4.30	3.59	2.95	3.02	3.35	5.10
Cleft lip with or without cleft palate	10.74	11.84	10.14	9.21	7.89	6.54	7.28	7.28
Oesophageal atresia/stenosis with or without fistula	2.41*	1.89	1.66	1.79	1.03	0.88	1.38	2.45
Small intestine atresia/stenosis	nr	1.50*	1.42	1.16	0.82	0.53	1.13	2.41
Anorectal atresia/stenosis	nr	2.37*	2.08	1.76	1.20	0.84	1.42	2.71
Undescended testis (36 weeks of gestation or later)	nr	14.97*	18.12	16.27	13.80	10.07	16.34	19.77
Hypospadias	15.68	16.95	22.04	21.00	20.32	20.02	25.16	26.90
Epispadias	nr	nr	nr	nr	nr	nr	nr	1.27*
Indeterminate sex	nr	0.27*	0.31	0.37	0.10	0.14	0.51	0.37
Renal agenesis	nr	1.36*	0.76	1.27	0.38	0.20	0.56	1.67
Cystic kidney	nr	0.00*	0.06	0.35	0.40	1.92	3.47	4.28
Bladder exstrophy	nr	0.14*	0.51	0.27	0.03	0.06	0.12	0.39
Polydactyly, preaxial	nr	0.00*	1.74	1.86	1.19	7.86	8.18	7.79
Total Limb reduction defects (include unspecified)	nr	nr	4.44	3.62	2.75	3.06	3.27	3.28
Transverse	nr	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	2.75	1.55	2.30	2.16	0.94	0.84	1.15	2.43
Omphalocele	nr	nr	1.99	0.95	0.64	0.94	1.21	1.57
Gastroschisis	nr	nr	0.54	0.56	0.44	0.84	0.86	1.08
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	nr	nr	0.00*
Prune belly sequence	nr	nr	nr	nr	0.00*	0.10	0.04	0.04
Trisomy 13	nr	nr	0.26	0.16	0.16	0.37	0.82	1.26
Trisomy 18	nr	nr	0.25	0.33	0.19	1.04	1.85	3.20
Down syndrome, all ages (include age unknown)	8.92	8.95	7.77	8.54	7.62	10.05	14.68	19.06
<20	nr	nr	1.56	2.52	1.30	3.05	8.26	9.51
20-24	nr	nr	2.04	3.03	1.95	4.32	8.22	5.52
25-29	nr	nr	3.46	4.25	2.37	6.22	7.34	8.77
30-34	nr	nr	4.80	5.64	4.17	9.28	13.46	13.49
35-39	nr	nr	11.04	18.96	17.57	26.56	43.02	49.46
40-44	nr	nr	56.53	64.97	70.18	145.25	156.14	120.70
45+	nr	nr	nr	nr	nr	nr	nr	237.58*
unknown	---	---	---	---	---	---	---	---

nr = data not reported or not available
* data include less than 3 years or 5 years

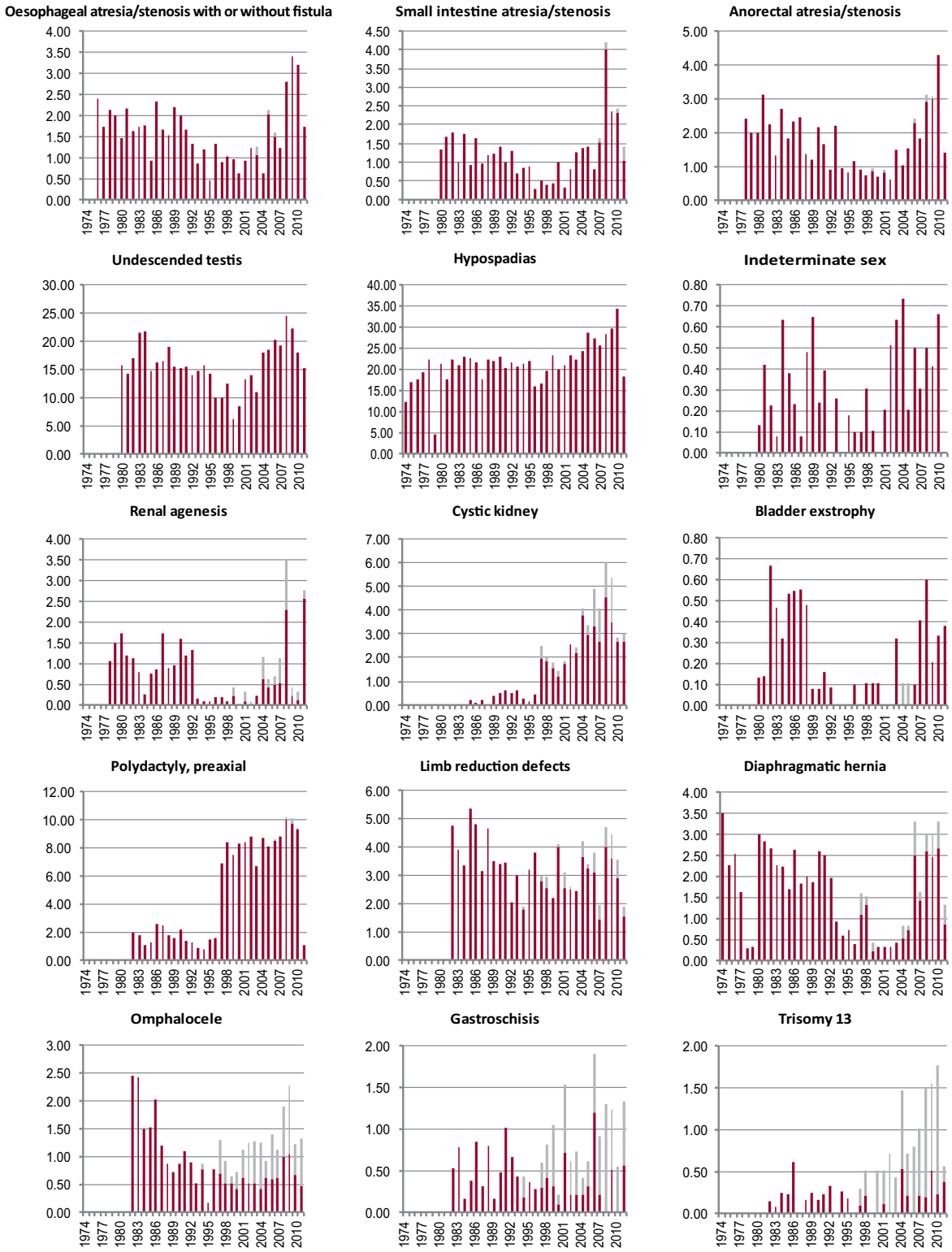
Hungary

Time trends 1974-2011 (Birth prevalence rates per 10,000)



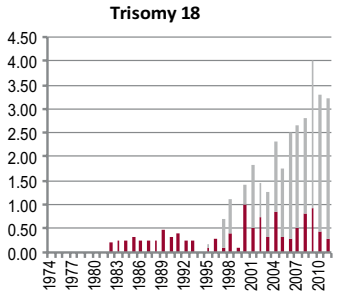
Note: L+S rates, ToP rates

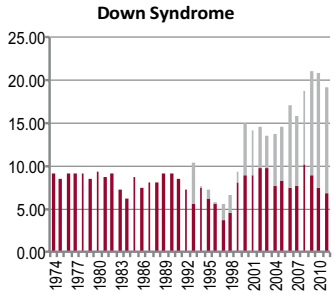
Hungary

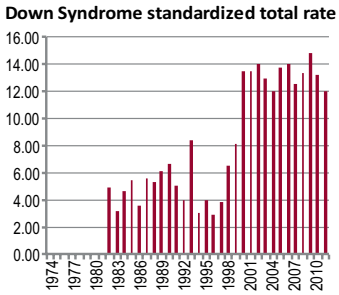


Note: L+S rates, ToP rates

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:
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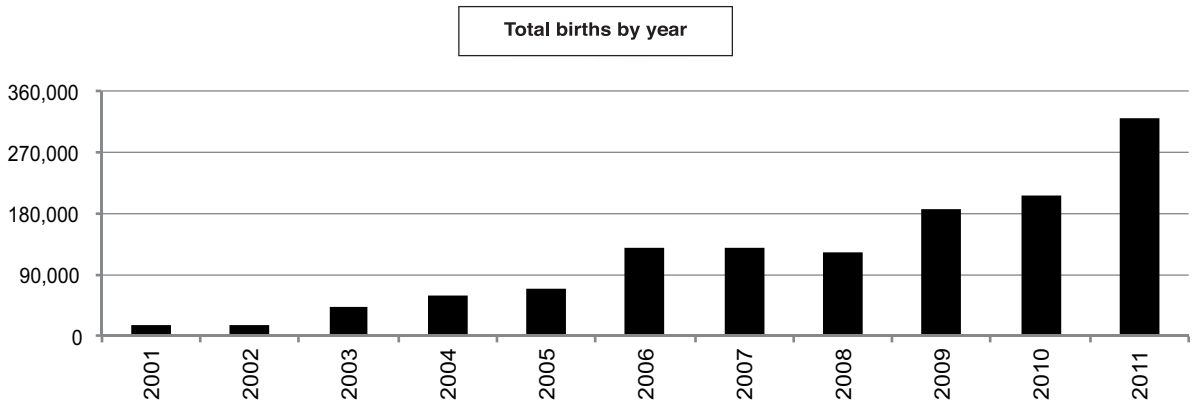
Director, Birth Defects Registry Of India
Managing Director, MediScan Systems
197, Dr Natesan Road
Mylapore, Chennai – 4
India
E-mail: mediscan@gmail.com
Website: www.mediscansystems.org.in

India: BDRI



Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	390	51.0	Cystic kidney	63	36.2
Spina bifida	244	34.8	Limb reduction defects	33	21.7
Encephalocele	65	49.2	Diaphragmatic hernia	36	22.1
Holoprosencephaly	32	48.5	Omphalocele	59	44.4
Hydrocephaly	151	26.2	Gastroschisis	30	51.7
Hypoplastic left heart syndrome	26	56.5	Trisomy 13	4	66.7
Cleft palate without cleft lip	8	8.5	Trisomy 18	2	20.0
Cleft lip with or without cleft palate	32	13.7	Down syndrome	23	39.0
Renal agenesis	29	40.3			

Total ToPs with births defects = 1,475 (Ratio ToPs/Births: 2.07 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

India: BDRI, 2011

Live births (LB)	310,184
Stillbirths (SB)	10,126
Total births	320,310
Number of terminations of pregnancy (ToP) for birth defects	530

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	48	120	167	10.46
Spina bifida	100	64	76	7.49
Encephalocele	15	12	22	1.53
Microcephaly	13	6	0	0.59
Holoprosencephaly	8	5	6	0.59
Hydrocephaly	117	65	50	7.24
Anophthalmos	2	0	0	0.06
Microphthalmos	4	1	2	0.22
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	1	0	0	0.03
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	4	0	3	0.22
Tetralogy of Fallot	6	3	3	0.37
Hypoplastic left heart syndrome	3	1	4	0.25
Coarctation of aorta	1	0	0	0.03
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	23	3	2	0.87
Cleft lip with or without cleft palate	79	14	5	3.06
Oesophageal atresia/stenosis with or without fistula	12	3	1	0.50
Small intestine atresia/stenosis	7	2	2	0.34
Anorectal atresia/stenosis	19	3	3	0.78
Undescended testis (36 weeks of gestation or later)	11	3	0	0.44
Hypospadias	40	0	0	1.25
Epispadias	0	0	0	0.00
Indeterminate sex	9	4	0	0.41
Renal agenesis	11	6	10	0.84
Cystic kidney	21	16	25	1.94
Bladder exstrophy	2	2	6	0.31
Polydactyly, preaxial	27	7	3	1.16
Total Limb reduction defects (include unspecified)	21	11	12	1.37
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	35	6	9	1.56
Omphalocele	20	10	16	1.44
Gastroschisis	8	3	11	0.69
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.03
Trisomy 13	0	0	1	0.03
Trisomy 18	0	2	0	0.06
Down syndrome, all ages (include age unknown)	11	1	10	0.69
<20	1	0	nr	nr
20-24	3	1	0	nr
25-29	4	0	1	nr
30-34	0	0	2	nr
35-39	0	0	1	nr
40-44	0	0	0	nr
45+	0	0	0	nr
unknown	3	0	6	---

nr = data not reported or not available

India: BDRI, Previous years rates 2001 - 2011

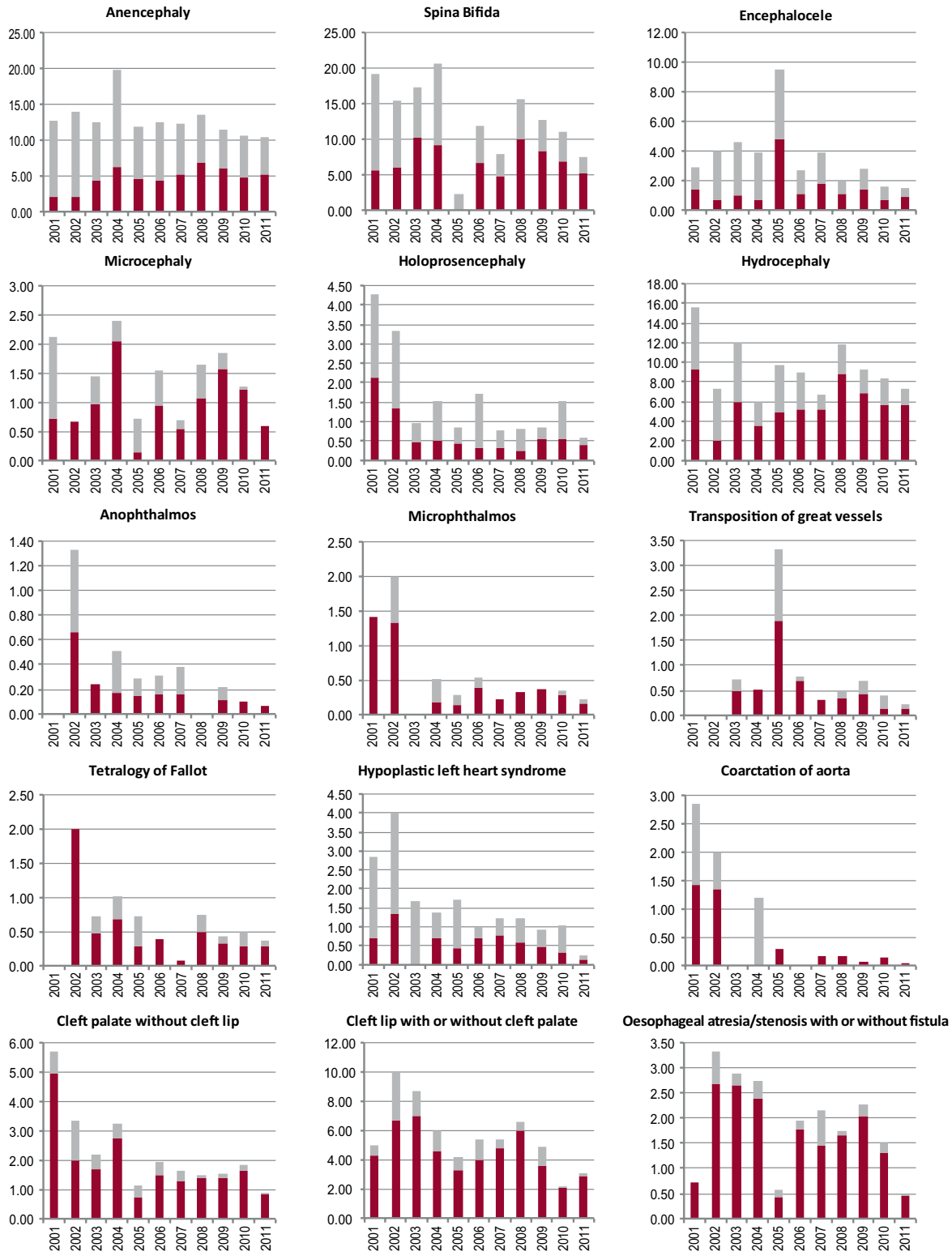
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001*	2002-2006	2007-2011
Total births						**14,084**	**313,042**	**962,390**
Anencephaly						12.78	13.77	11.29
Spina bifida						19.17	12.33	10.33
Encephalocele						2.84	4.76	2.14
Microcephaly						2.13	1.47	1.12
Holoprosencephaly						4.26	1.47	0.89
Hydrocephaly						15.62	8.91	8.40
Anophthalmos						0.00	0.38	0.14
Microphthalmos						1.42	0.48	0.29
Unspecified Anophthalmos/Microphthalmos						0.00	0.00	0.01
Anotia						0.00	0.00	0.06
Microtia						0.00	0.03	0.12
Unspecified Anotia/Microtia						0.00	0.00	0.00
Transposition of great vessels						0.00	1.25	0.39
Tetralogy of Fallot						0.00	0.70	0.42
Hypoplastic left heart syndrome						2.84	1.47	0.80
Coarctation of aorta						2.84	0.38	0.09
Choanal atresia, bilateral						0.00	0.19	0.02
Cleft palate without cleft lip						5.68	2.11	1.38
Cleft lip with or without cleft palate						4.97	5.88	3.98
Oesophageal atresia/stenosis with or without fistula						0.71	1.98	1.43
Small intestine atresia/stenosis						2.84	0.38	0.69
Anorectal atresia/stenosis						0.71	1.25	1.54
Undescended testis (36 weeks of gestation or later)						0.71	0.93	0.85
Hypospadias						3.55	1.92	1.67
Epispadias						0.00	0.00	0.01
Indeterminate sex						4.97	2.11	1.03
Renal agenesis						4.26	2.56	1.18
Cystic kidney						14.91	3.32	2.69
Bladder exstrophy						2.84	0.45	0.48
Polydactyly, preaxial						3.55	3.16	2.52
Total Limb reduction defects (include unspecified)						16.33	9.58	2.10
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						8.52	2.94	2.36
Omphalocele						4.26	2.78	1.98
Gastroschisis						1.42	0.64	0.76
Unspecified Omphalocele/Gastroschisis						0.00	0.13	0.03
Prune belly sequence						1.42	0.06	0.19
Trisomy 13						0.00	0.16	0.06
Trisomy 18						0.00	0.58	0.18
Down syndrome, all ages (include age unknown)						0.00	1.02	0.90
<20						nr	nr	nr
20-24						nr	nr	nr
25-29						nr	nr	nr
30-34						nr	nr	nr
35-39						nr	nr	nr
40-44						nr	nr	nr
45+						nr	nr	nr
unknown						---	---	---

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

India: BDRI

Time trends 2001-2011 (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:
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Programme Director
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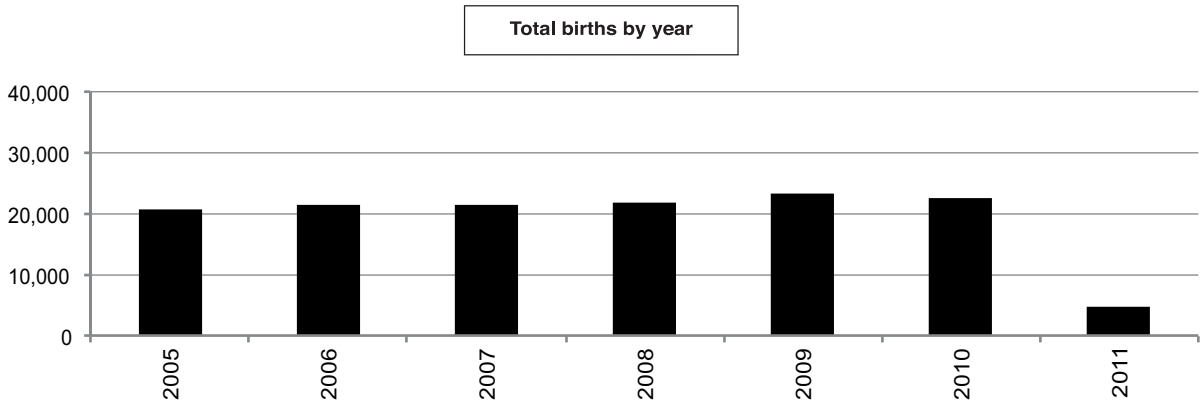
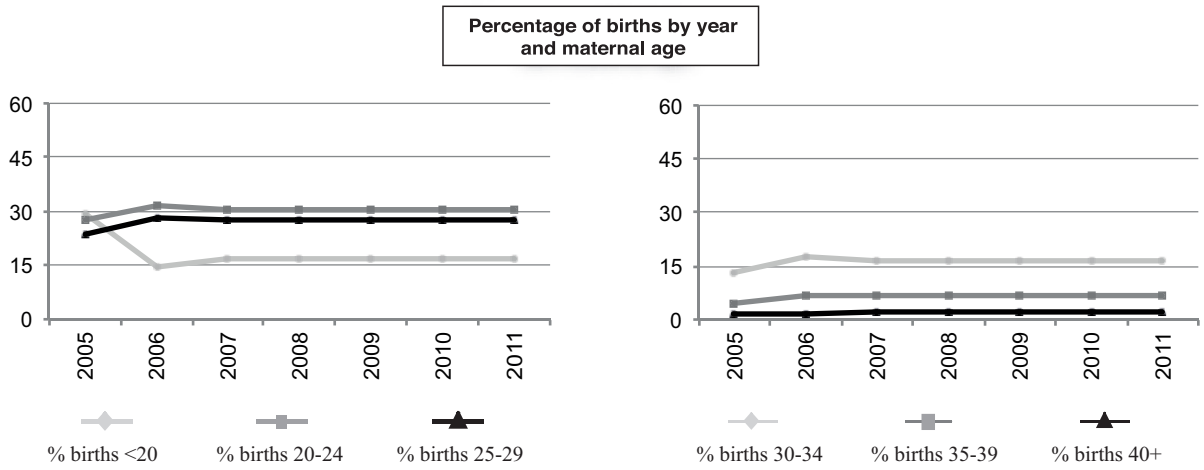
Tabriz University of Medical Sciences
Tabriz, Iran
Phone: 98-914 415 7039
Fax: 98-411 336 4668
E-mail: saeed.dastgiri@gmail.com
Website: http://troca.tbzmed.ac.ir

Iran: TRoCA


Total births by year
40,000
30,000
20,000
10,000
0
2005
2006
2007
2008
2009
2010
2011


Percentage of births by year and maternal age
60
45
30
15
0
2005
2006
2007
2008
2009
2010
2011
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Iran: TRoCA, 2011(*)

Live births (LB)	4,839
Stillbirths (SB)	48
Total births	4,887
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	nr	nr	nr	nr
Spina bifida	1	nr	nr	2.05
Encephalocele	1	1	nr	4.09
Microcephaly	11	nr	nr	22.51
Holoprosencephaly	nr	1	nr	2.05
Hydrocephaly	9	2	nr	22.51
Anophthalmos	nr	nr	nr	nr
Microphthalmos	4	nr	nr	8.18
Unspecified Anophthalmos/Microphthalmos	13	nr	nr	26.60
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	16	nr	nr	32.74
Transposition of great vessels	2	nr	nr	4.09
Tetralogy of Fallot	nr	nr	nr	nr
Hypoplastic left heart syndrome	1	nr	nr	2.05
Coarctation of aorta	4	nr	nr	8.18
Choanal atresia, bilateral	nr	nr	nr	nr
Cleft palate without cleft lip	9	nr	nr	18.42
Cleft lip with or without cleft palate	14	2	nr	32.74
Oesophageal atresia/stenosis with or without fistula	8	nr	nr	16.37
Small intestine atresia/stenosis	9	1	nr	20.46
Anorectal atresia/stenosis	7	nr	nr	14.32
Undescended testis (36 weeks of gestation or later)	1	nr	nr	2.05
Hypospadias	33	nr	nr	67.53
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	nr	nr	nr	nr
Cystic kidney	5	nr	nr	10.23
Bladder exstrophy	nr	nr	nr	nr
Polydactyly, preaxial	10	1	nr	22.51
Total Limb reduction defects (include unspecified)	76	2	nr	159.61
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	nr	nr	22.51
Omphalocele	2	nr	nr	4.09
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	2	1	nr	6.14
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	nr	nr	nr	nr
Trisomy 18	nr	nr	nr	nr
Down syndrome, all ages (include age unknown)	8	nr	nr	nr
<20	nr	nr	nr	nr
20-24	1	nr	nr	nr
25-29	1	nr	nr	nr
30-34	4	nr	nr	nr
35-39	2	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = data not reported or not available
(*) Data from one of the hospitals of TRoCA, about 40% of the population definited in the program

Iran: TRoCA, Previous years rates 2005 - 2011

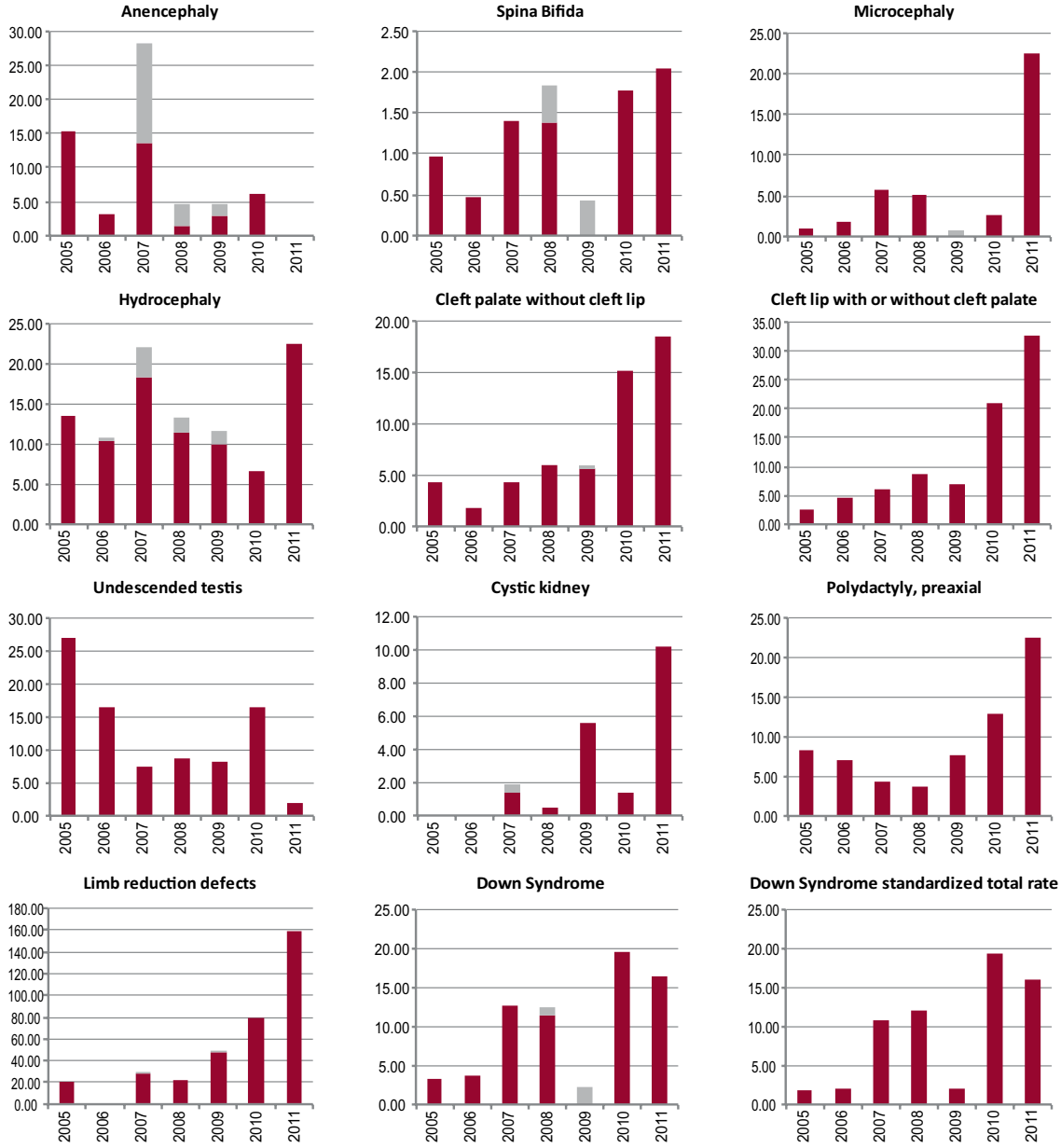
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006*	2007-2011
Total births							**42,048**	**88,676**
Anencephaly							9.28	10.71*
Spina bifida							0.71	1.39*
Encephalocele							1.90	1.00*
Microcephaly							1.43	4.49*
Holoprosencephaly							nr	2.05*
Hydrocephaly							12.13	13.79*
Anophthalmos							0.47	nr
Microphthalmos							0.48	2.05*
Unspecified Anophthalmos/Microphthalmos							0.71	5.55*
Anotia							nr	nr
Microtia							nr	1.81*
Unspecified Anotia/Microtia							0.94	9.57*
Transposition of great vessels							0.48	7.94*
Tetralogy of Fallot							0.47	1.36*
Hypoplastic left heart syndrome							nr	3.67*
Coarctation of aorta							nr	2.92*
Choanal atresia, bilateral							nr	nr
Cleft palate without cleft lip							3.09	8.44
Cleft lip with or without cleft palate							3.57	13.5*
Oesophageal atresia/stenosis with or without fistula							2.85	17.76*
Small intestine atresia/stenosis							nr	12.83*
Anorectal atresia/stenosis							1.19	10.94*
Undescended testis (36 weeks of gestation or later)							21.64	10.37*
Hypospadias							9.28	19.75*
Epispadias							nr	0.68*
Indeterminate sex							nr	1.78*
Renal agenesis							0.97	1.37*
Cystic kidney							nr	1.85*
Bladder exstrophy							nr	nr
Polydactyly, preaxial							7.61	8.10*
Total Limb reduction defects (include unspecified)							20.29	50.98
Transverse							nr	nr
Preaxial							nr	nr
Postaxial							nr	nr
Intercalary							nr	nr
Mixed							nr	nr
Unspecified							20.29	nr
Diaphragmatic hernia							0.94	8.38*
Omphalocele							0.48	1.81*
Gastroschisis							nr	nr
Unspecified Omphalocele/Gastroschisis							nr	2.90*
Prune belly sequence							nr	nr
Trisomy 13							nr	1.13*
Trisomy 18							0.71	0.93*
Down syndrome, all ages (include age unknown)							3.57	11.86
<20							1.09	6.66*
20-24							1.75	6.00
25-29							0.00	17.10*
30-34							3.08	12.93
35-39							8.65	22.20
40-44							17.57	72.46*
45+							0.00	95.69*
unknown							---	---

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

Iran: TRoCA

Time trends 2001-2011 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP 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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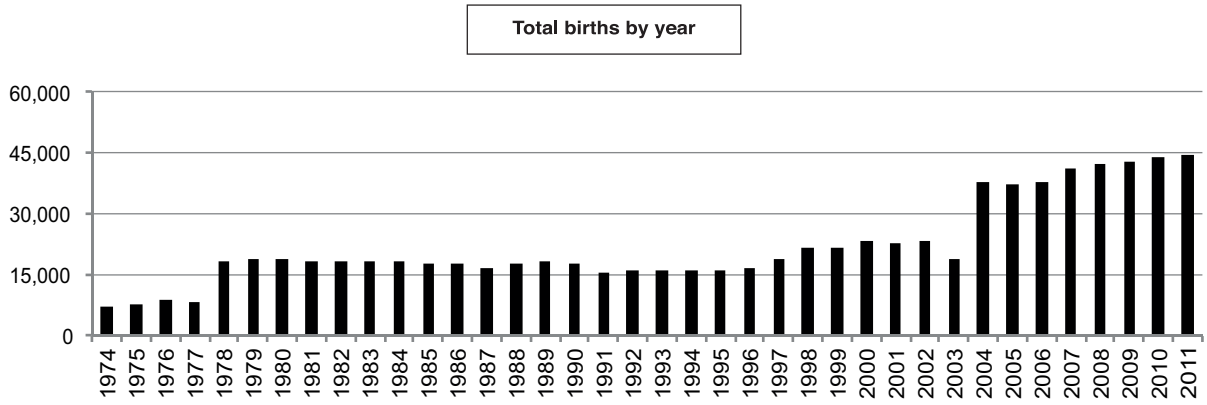
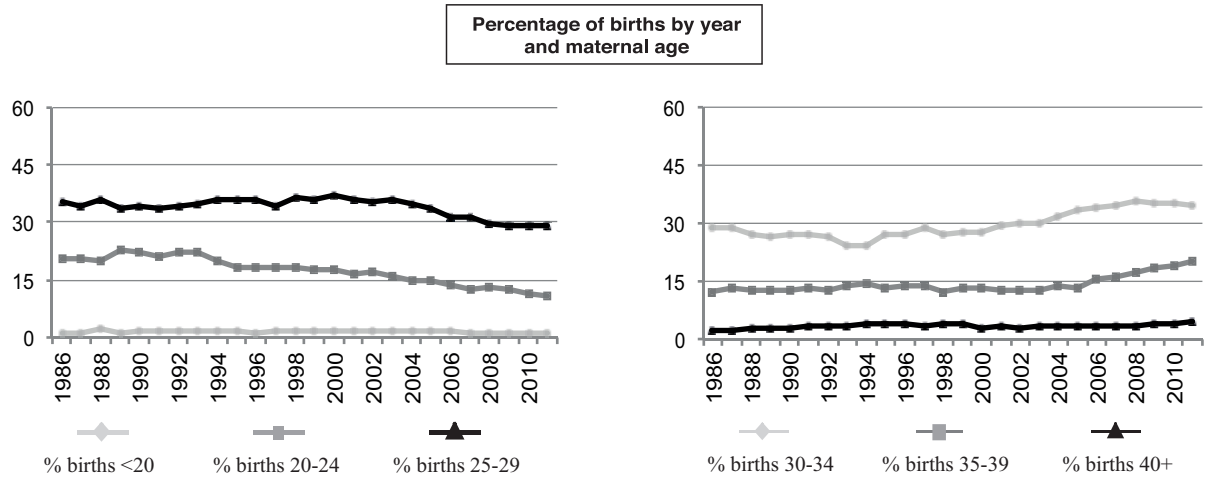
E-mail: davidbade@gmail.com

Israel: IBDSP





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	1	9.1	Cystic kidney	0	0.0
Spina bifida	3	10.3	Limb reduction defects	1	10.0
Encephalocele	0	0.0	Diaphragmatic hernia	1	5.3
Holoprosencephaly	0	0.0	Omphalocele	0	0.0
Hydrocephaly	7	20.0	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	0	0.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	0	0.0
Cleft lip with or without cleft palate	1	7.7	Down syndrome	7	10.6
Renal agenesis	0	0.0			

(*) % of ToPs = ToPs/(ToPs+Births)

Israel: IBDSP, 2011

Live births (LB)	44,140
Stillbirths (SB)	309
Total births	44,449
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	0.45
Spina bifida	9	2	nr	2.47
Encephalocele	0	nr	nr	0.00
Microcephaly	20	nr	nr	4.50
Holoprosencephaly	0	nr	nr	0.00
Hydrocephaly	14	nr	nr	3.15
Anophthalmos	0	nr	nr	0.00
Microphthalmos	1	1	nr	0.45
Unspecified Anophthalmos/Microphthalmos	0	nr	nr	0.00
Anotia	0	nr	nr	0.00
Microtia	0	nr	nr	0.00
Unspecified Anotia/Microtia	0	nr	nr	0.00
Transposition of great vessels	16	nr	nr	3.60
Tetralogy of Fallot	12	nr	nr	2.70
Hypoplastic left heart syndrome	12	2	nr	3.15
Coarctation of aorta	12	nr	nr	2.70
Choanal atresia, bilateral	3	nr	nr	0.67
Cleft palate without cleft lip	24	4	nr	6.30
Cleft lip with or without cleft palate	18	nr	nr	4.05
Oesophageal atresia/stenosis with or without fistula	21	nr	nr	4.72
Small intestine atresia/stenosis	5	nr	nr	1.12
Anorectal atresia/stenosis	6	nr	nr	1.35
Undescended testis (36 weeks of gestation or later)	60	nr	nr	13.50
Hypospadias	125	nr	nr	28.12
Epispadias	0	nr	nr	0.00
Indeterminate sex	0	nr	nr	0.00
Renal agenesis	1	nr	nr	0.22
Cystic kidney	5	nr	nr	1.12
Bladder exstrophy	0	nr	nr	0.00
Polydactyly, preaxial	1	nr	nr	0.22
Total Limb reduction defects (include unspecified)	0	nr	nr	0.00
Transverse	0	nr	nr	0.00
Preaxial	0	nr	nr	0.00
Postaxial	0	nr	nr	0.00
Intercalary	0	nr	nr	0.00
Mixed	0	nr	nr	0.00
Unspecified	0	nr	nr	0.00
Diaphragmatic hernia	13	nr	nr	2.92
Omphalocele	8	nr	nr	1.80
Gastroschisis	0	nr	nr	0.00
Unspecified Omphalocele/Gastroschisis	0	nr	nr	0.00
Prune belly sequence	0	nr	nr	0.00
Trisomy 13	0	nr	nr	0.00
Trisomy 18	2	nr	nr	0.45
Down syndrome, all ages (include age unknown)	24	nr	nr	5.40
<20	0	nr	nr	0.00
20-24	0	nr	nr	0.00
25-29	3	nr	nr	2.31
30-34	10	nr	nr	6.51
35-39	7	nr	nr	7.91
40-44	4	nr	nr	22.27
45+	0	nr	nr	0.00
unknown	0	nr	nr	---

nr = data not reported or not available

Israel: IBDSP, Previous years rates 1974 - 2011

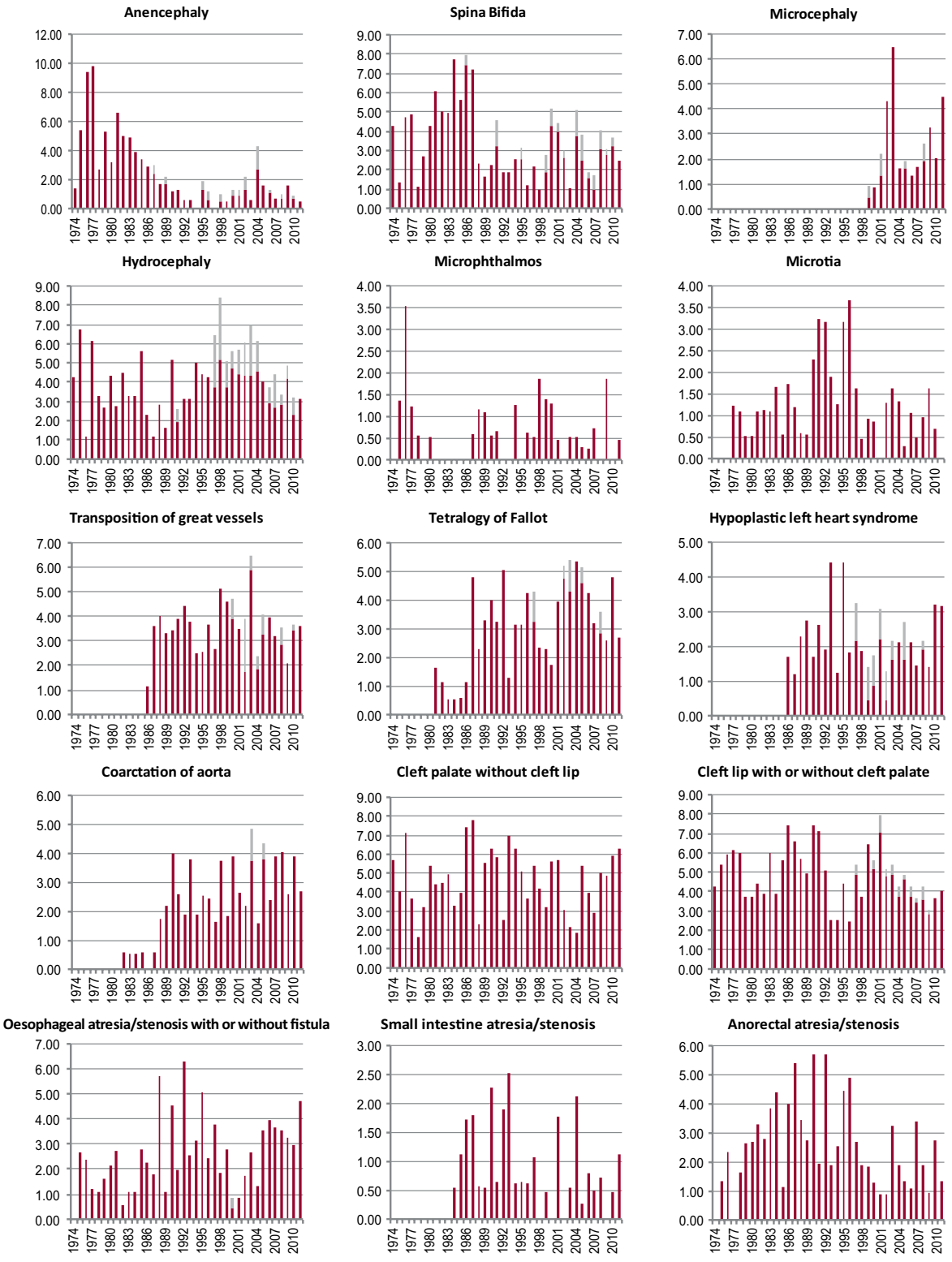
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**22,957**	**82,159**	**89,839**	**85,221**	**79,784**	**107,578**	**153,922**	**214,118**
Anencephaly	5.66	4.99	4.01	1.88	0.88	0.84	2.14	0.93
Spina bifida	3.48	3.65	6.23	3.52	2.13	3.16	3.18	2.99
Encephalocele	0.44	0.24	0.45	0.94	0.63	0.28	0.39	0.33
Microcephaly	nr	nr	0.00*	0.00	0.00	0.84	2.60	2.85
Holoprosencephaly	nr	nr	0.19*	0.23	0.38	0.00	0.39	0.23
Hydrocephaly	3.92	3.53	3.78	2.70	4.01	6.23	5.13	3.78
Anophthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.13	0.14
Microphthalmos	1.74	0.37	0.00	0.82	0.38	1.12	0.32	0.61
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.00	0.00	0.00	0.00	0.13	0.00	0.00	0.05
Microtia	0.00	0.85	1.22	1.53	2.63	0.74	1.04	0.75
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	nr	1.14*	3.64	3.38	4.18	3.90	3.22
Tetralogy of Fallot	nr	0.81*	0.78	3.52	3.38	2.88	5.00	3.36
Hypoplastic left heart syndrome	nr	nr	1.71*	2.11	2.76	2.23	2.14	2.29
Coarctation of aorta	nr	0.00*	0.45	2.23	2.51	2.79	2.92	3.41
Choanal atresia, bilateral	nr	nr	0.37*	0.12	0.25	0.28	0.06	0.23
Cleft palate without cleft lip	5.66	3.65	4.79	5.52	4.89	4.83	3.44	5.04
Cleft lip with or without cleft palate	5.23	4.63	5.34	6.34	3.38	5.86	4.68	3.74
Oesophageal atresia/stenosis with or without fistula	1.74	1.83	1.56	3.05	3.89	1.95	2.73	3.64
Small intestine atresia/stenosis	nr	nr	1.12*	1.17	1.25	0.65	0.84	0.56
Anorectal atresia/stenosis	1.31	2.31	3.23	3.87	3.89	1.67	1.56	2.05
Undescended testis (36 weeks of gestation or later)	nr	nr	0.00*	0.00	0.00	0.00*	nr	9.69*
Hypospadias	34.41	26.90	27.16	37.55	39.73	36.90	32.48	35.82
Epispadias	0.44	0.00	0.11	0.00	0.25	0.19	0.19	0.09
Indeterminate sex	nr	nr	0.00*	0.00	0.00	0.00*	0.27	0.29*
Renal agenesis	nr	nr	0.57*	0.82	0.63	0.46	1.30	0.51
Cystic kidney	0.87	0.49	0.89	1.41	0.88	1.77	2.08	2.15
Bladder exstrophy	0.00	0.24	0.22	0.82	0.25	0.28	0.45	0.23
Polydactyly, preaxial	0.44	0.24	0.56	0.47	0.75	1.12	0.78	0.75
Total Limb reduction defects (include unspecified)	3.92	3.16	2.89	2.70	3.01	1.02	2.66	1.35
Transverse	nr	nr	0.78	1.64	1.00	0.37	1.30	0.65
Preaxial	nr	nr	0.67	0.47	0.38	0.46	0.91	0.19
Postaxial	nr	nr	0.33	0.12	0.75	0.00	0.13	0.23
Intercalary	nr	nr	0.45	0.12	0.25	0.19	0.26	0.09
Mixed	nr	nr	0.67	0.35	0.63	0.00	0.06	0.09
Unspecified	nr	nr	0.00	0.00	0.00	0.00	0.00	0.09
Diaphragmatic hernia	nr	nr	2.67	2.11	2.13	1.77	1.82	2.24
Omphalocele	2.61	1.83	2.00	1.06	0.75	0.56	1.10	0.75
Gastroschisis	nr	nr	0.78	0.12	0.00	0.28	0.26	0.19
Unspecified Omphalocele/Gastroschisis	nr	nr	0.00	0.00	0.00	0.19	0.00	0.00
Prune belly sequence	0.87	0.24	0.11	0.12	0.00	0.09	0.26	0.05
Trisomy 13	nr	nr	0.56*	0.47	0.25	0.65	0.39	0.23
Trisomy 18	nr	nr	0.56*	0.70	1.00	0.93	1.17	0.56
Down syndrome, all ages (include age unknown)	13.07	9.49	12.02	10.44	6.52	9.30	9.75	7.15
<20	nr	nr	nr	0.00*	0.00	0.00	15.11	0.00*
20-24	nr	nr	nr	0.00*	0.63	3.16	3.91	3.87*
25-29	nr	nr	nr	0.00*	3.89	5.17	4.77	2.95*
30-34	nr	nr	nr	9.62	5.36	8.59	6.46	3.15*
35-39	nr	nr	nr	24.73	14.78	17.23	19.75	10.78*
40-44	nr	nr	nr	60.98	33.58	62.46	75.98	53.56*
45+	nr	nr	nr	0.00*	95.54	87.46	80.00	49.32*
unknown	---	---	---	---	---	---	---	---

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

Israel: IBDSP

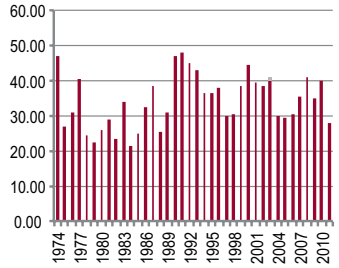
Time trends 1974-2011 (Birth prevalence rates per 10,000)



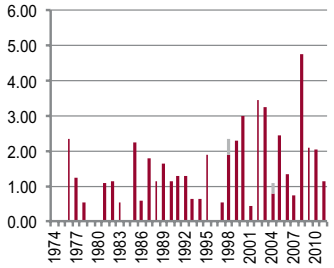
Note: L+S rates, ToP rates

Israel: IBDSP

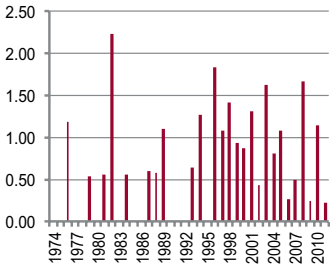
Hypospadias



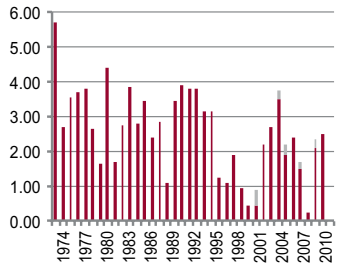
Cystic kidney



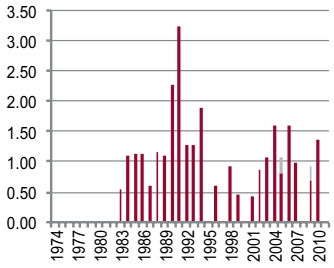
Polydactyly, preaxial



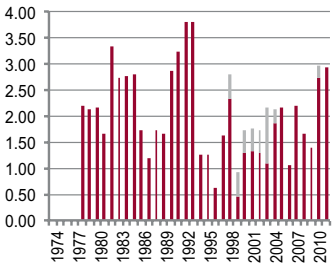
Limb reduction defects



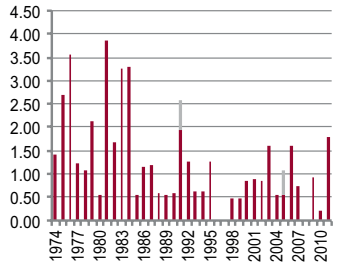
Limb reduction defects - transverse



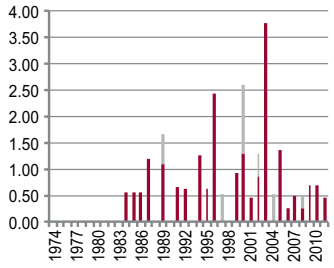
Diaphragmatic hernia



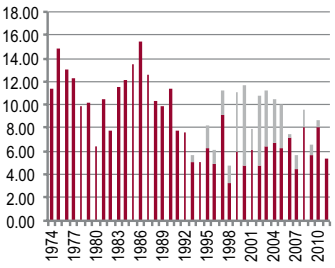
Omphalocele



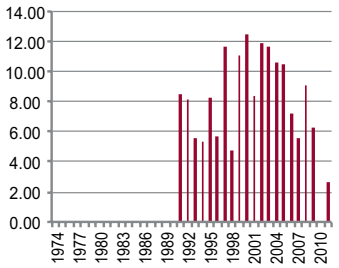
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

ITALY-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, 2011(*)

Live births (LB)	8,165
Stillbirths (SB)	11
Total births	8,176
Number of terminations of pregnancy (ToP) for birth defects	30

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	1	1.22
Spina bifida	1	0	3	4.89
Encephalocele	0	0	0	0.00
Microcephaly	2	0	0	2.45
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	1	2	5	9.78
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	3.67
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	1	0	0	1.22
Tetralogy of Fallot	0	0	0	0.00
Hypoplastic left heart syndrome	0	0	1	1.22
Coarctation of aorta	5	0	0	6.12
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	3	0	0	3.67
Cleft lip with or without cleft palate	3	0	0	3.67
Oesophageal atresia/stenosis with or without fistula	2	0	0	2.45
Small intestine atresia/stenosis	1	0	0	1.22
Anorectal atresia/stenosis	3	0	1	4.89
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	22	0	0	26.91
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	3	0	2	6.12
Cystic kidney	2	0	0	2.45
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	4	0	1	6.12
Total Limb reduction defects (include unspecified)	4	1	3	9.78
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	3	0	0	3.67
Omphalocele	0	0	2	2.45
Gastroschisis	0	1	1	2.45
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	2	2.45
Trisomy 18	1	0	8	11.01
Down syndrome, all ages (include age unknown)	14	0	10	29.39
<20	0	0	0	0.00
20-24	2	0	1	45.80
25-29	1	0	0	5.89
30-34	2	0	1	10.42
35-39	5	0	4	39.16
40-44	4	0	4	154.74
45+	0	0	0	0.00
unknown	0	0	0	---

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

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 member of Eurocat in 1985, and 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.

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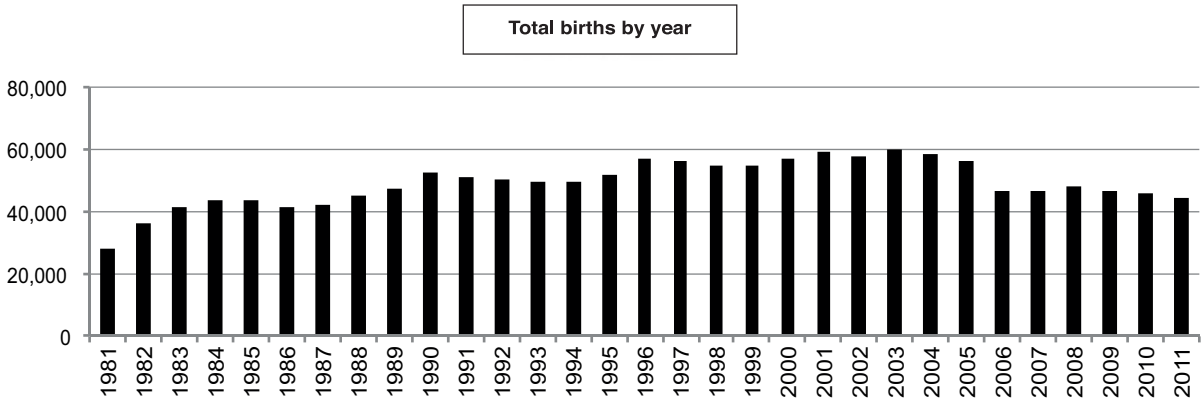
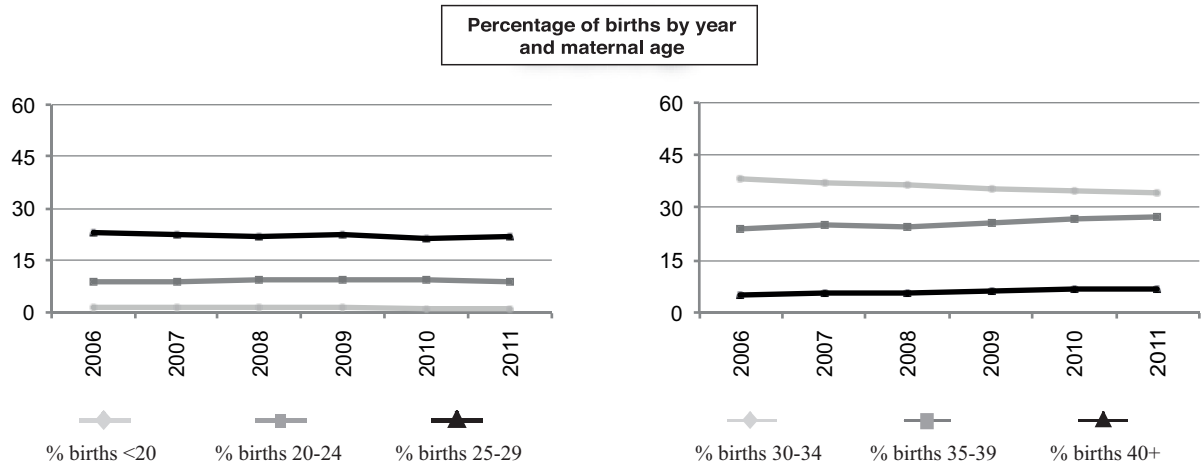
Italy-North East





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	9	90.0	Cystic kidney	3	23.1
Spina bifida	14	70.0	Limb reduction defects	4	14.8
Encephalocele	3	75.0	Diaphragmatic hernia	3	13.6
Holoprosencephaly	3	100.0	Omphalocele	5	35.7
Hydrocephaly	13	44.8	Gastroschisis	4	25.0
Hypoplastic left heart syndrome	9	47.4	Trisomy 13	3	75.0
Cleft palate without cleft lip	7	12.3	Trisomy 18	13	100.0
Cleft lip with or without cleft palate	12	14.3	Down syndrome	92	36.8
Renal agenesis	7	36.8			

Total ToPs with births defects = 199 (Ratio ToPs/Births: 1.45 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy-North East, 2011

Live births (LB)	44,322
Stillbirths (SB)	138
Total births	44,460
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	1	0.22
Spina bifida	3	0	7	2.25
Encephalocele	1	0	1	0.45
Microcephaly	1	0	0	0.22
Holoprosencephaly	0	0	1	0.22
Hydrocephaly	5	0	3	1.80
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.22
Microtia	4	0	0	0.90
Unspecified Anotia/Microtia	0	0	1	0.22
Transposition of great vessels	15	0	2	3.82
Tetralogy of Fallot	9	0	0	2.02
Hypoplastic left heart syndrome	6	0	3	2.02
Coarctation of aorta	8	0	0	1.80
Choanal atresia, bilateral	2	0	0	0.45
Cleft palate without cleft lip	13	0	3	3.60
Cleft lip with or without cleft palate	14	0	5	4.27
Oesophageal atresia/stenosis with or without fistula	14	0	2	3.60
Small intestine atresia/stenosis	18	0	0	4.05
Anorectal atresia/stenosis	5	0	1	1.35
Undescended testis (36 weeks of gestation or later)	0	0	0	0.00
Hypospadias	9	0	1	2.25
Epispadias	2	0	0	0.45
Indeterminate sex	1	0	0	0.22
Renal agenesis	0	0	1	0.22
Cystic kidney	0	0	1	0.22
Bladder exstrophy	1	0	0	0.22
Polydactyly, preaxial	4	0	0	0.90
Total Limb reduction defects (include unspecified)	7	0	2	2.02
Transverse	5	0	1	1.35
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	2	0	1	0.67
Diaphragmatic hernia	8	0	2	2.25
Omphalocele	2	0	1	0.67
Gastroschisis	2	0	0	0.45
Unspecified Omphalocele/Gastroschisis	0	0	1	0.22
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	0	0.00
Trisomy 18	0	0	5	1.12
Down syndrome, all ages (include age unknown)	43	0	28	15.97
<20	0	0	0	0.00
20-24	1	0	0	2.52
25-29	4	0	7	11.37
30-34	8	0	7	9.86
35-39	13	0	9	18.25
40-44	17	0	4	71.84
45+	0	0	0	0.00
unknown	0	0	1	---

nr = data not reported or not available

Italy-North East, Previous years rates 1981 - 2011

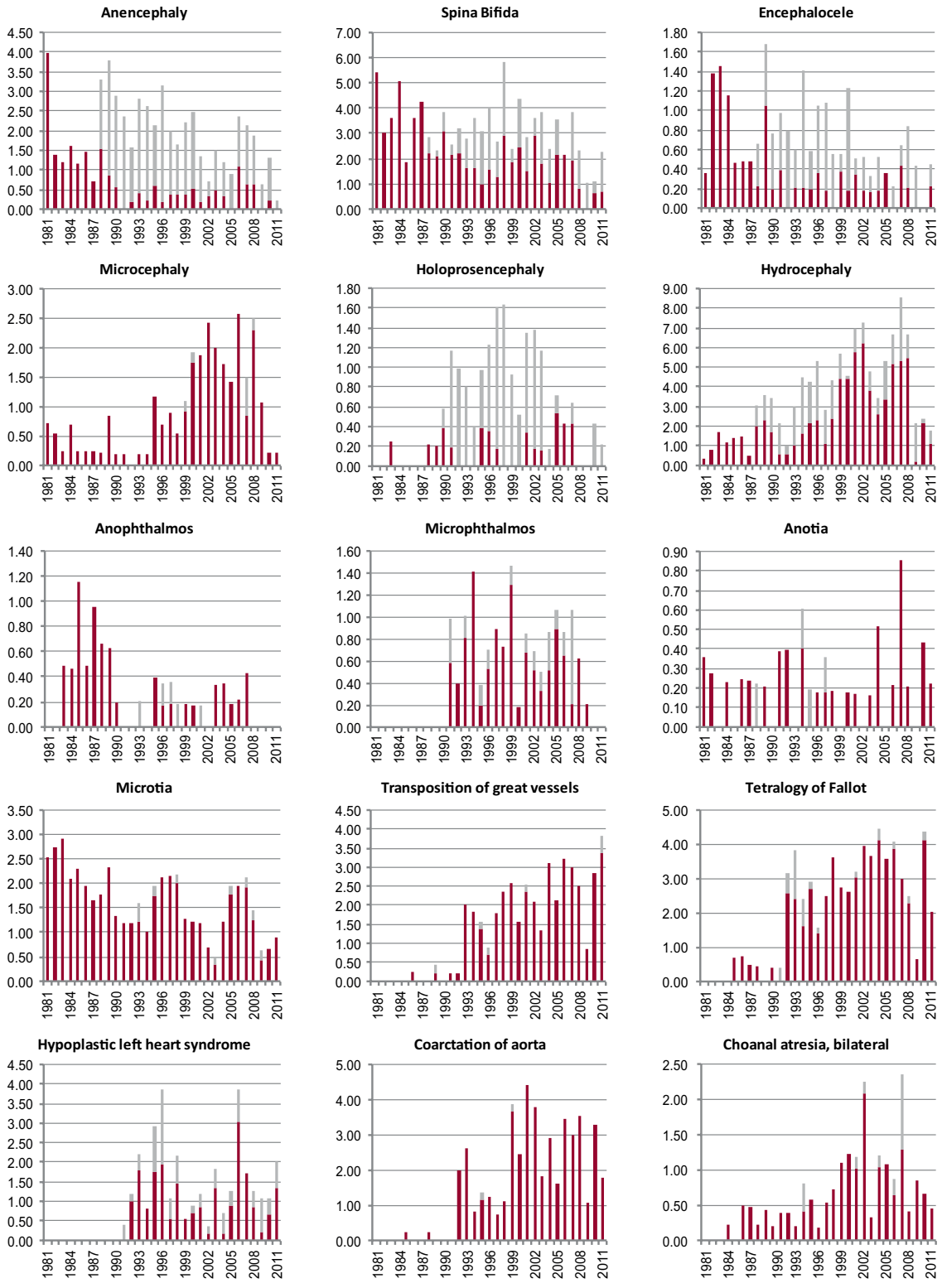
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**27,708**	**205,384**	**238,168**	**257,873**	**281,208**	**278,677**	**231,878**
Anencephaly		3.97	1.36	2.65	2.48	1.92	1.29	1.25
Spina bifida		5.41	3.46	3.15	3.37	3.63	3.16	2.11
Encephalocele		0.36	0.97	0.92	0.89	0.78	0.39	0.47
Microcephaly		0.72	0.39	0.34	0.47	1.28	2.01	1.12
Holoprosencephaly		0.00	0.05	0.46	0.89	1.21	0.79	0.26
Hydrocephaly		0.36	1.31	2.60	3.65	4.91	5.45	4.36
Anophthalmos		0.00	0.54	0.46	0.19	0.21	0.22	0.09
Microphthalmos		0.00	0.00	0.21	0.78	0.82	0.79	0.39
Unspecified Anophthalmos/Microphthalmos		nr	nr	nr	nr	nr	nr	nr
Anotia		0.36	0.15	0.21	0.27	0.18	0.18	0.35
Microtia		2.53	2.39	1.64	1.59	1.60	1.22	1.16
Unspecified Anotia/Microtia		0.00	0.00	0.13	0.08	0.25	0.32	0.15
Transposition of great vessels		0.00	0.05	0.13	1.28	2.17	2.33	2.59
Tetralogy of Fallot		0.00	0.29	0.34	2.75	2.95	3.95	2.50
Hypoplastic left heart syndrome		0.00	0.00	0.08	2.25	1.17	1.51	1.42
Coarctation of aorta		0.00	0.05	0.04	1.59	2.52	2.69	2.54
Choanal atresia, bilateral		0.00	0.15	0.34	0.43	0.96	1.15	0.95
Cleft palate without cleft lip		0.72	5.11	5.54	4.65	5.23	7.18	6.08
Cleft lip with or without cleft palate		11.55	8.72	8.40	7.72	7.22	9.04	8.37
Oesophageal atresia/stenosis with or without fistula		3.25	2.53	1.97	2.95	2.67	2.94	3.02
Small intestine atresia/stenosis		0.36	0.49	0.88	1.05	1.07	3.27	3.06
Anorectal atresia/stenosis		2.89	2.92	2.69	2.37	3.06	2.98	3.49
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr	nr
Hypospadias		10.83	5.79	7.05	6.01	15.90	20.38	12.25
Epispadias		0.00	0.15	0.08	0.12	0.32	0.14	0.26
Indeterminate sex		nr	nr	nr	nr	nr	nr	0.11*
Renal agenesis		0.36	0.73	0.92	0.39	0.64	0.72	3.15
Cystic kidney		0.00	0.00	0.00	0.50	0.92	1.18	2.50
Bladder exstrophy		0.36	0.19	0.42	0.19	0.25	0.25	0.35
Polydactyly, preaxial		1.80	1.90	2.60	2.17	1.78	2.37	4.18
Total Limb reduction defects (include unspecified)		6.14	5.75	6.34	5.24	4.98	4.16	2.89
Transverse		2.89	3.31	3.40	2.71	2.63	1.29*	1.66
Preaxial		0.00	0.00	0.34	0.85	0.57	0.34*	0.00*
Postaxial		0.00	0.05	0.13	0.19	0.25	0.21*	0.00*
Intercalary		1.08	0.58	0.97	0.70	0.39	0.21*	0.00*
Mixed		2.17	1.80	0.46	0.16	0.14	0.13*	0.00*
Unspecified		0.00	0.00	1.01	0.66	1.00	2.02*	0.55
Diaphragmatic hernia		0.36	0.63	0.42	0.62	1.24	1.94	1.94
Omphalocele		0.72	1.46	1.39	1.24	1.28	1.29	1.25
Gastroschisis		0.72	0.83	0.76	0.58	0.57	0.93	0.99
Unspecified Omphalocele/Gastroschisis		nr	nr	nr	nr	nr	0.21*	0.47
Prune belly sequence		0.00	0.05	0.08	0.43	0.04	0.00	0.00
Trisomy 13		1.44	0.78	0.55	0.93	1.07	1.26	0.39
Trisomy 18		1.08	1.22	1.72	2.56	2.60	1.94	0.99
Down syndrome, all ages (include age unknown)		15.52	14.46	16.12	16.67	16.86	17.26	19.92
<20		nr	nr	nr	nr	nr	16.29*	0.00
20-24		nr	nr	nr	nr	nr	4.94*	4.22
25-29		nr	nr	nr	nr	nr	3.75*	6.65
30-34		nr	nr	nr	nr	nr	7.90*	9.81
35-39		nr	nr	nr	nr	nr	19.89*	18.73
40-44		nr	nr	nr	nr	nr	58.43*	63.73
45+		nr	nr	nr	nr	nr	0.00*	133.84
unknown		---	---	---	---	---	---	---

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

Italy-North East

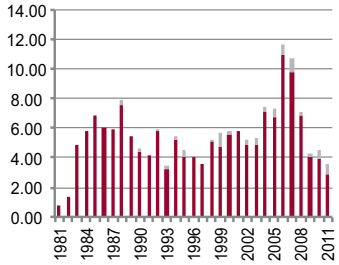
Time trends 1981-2011 (Birth prevalence rates per 10,000)



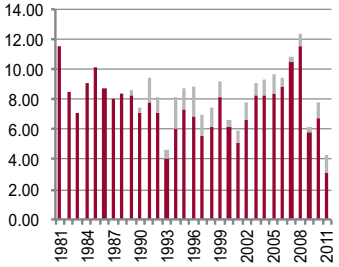
Note: L+S rates, ToP rates

Italy-North East

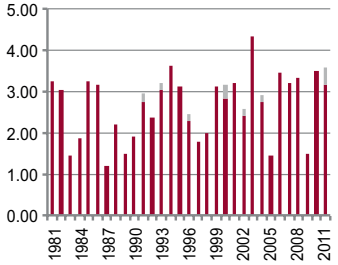
Cleft palate without cleft lip



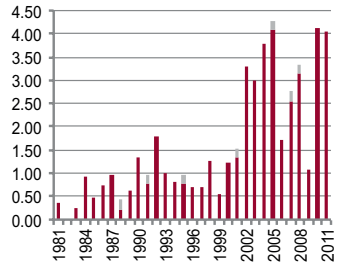
Cleft lip with or without cleft palate



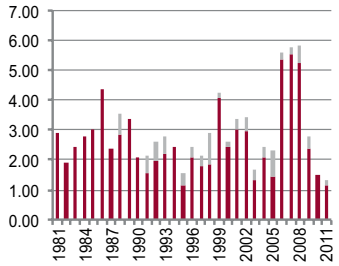
Oesophageal atresia/stenosis with or without fistula



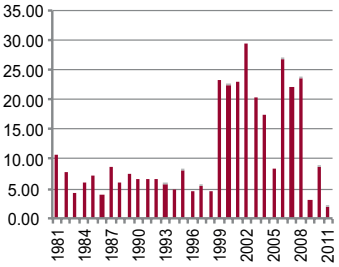
Small intestine atresia/stenosis



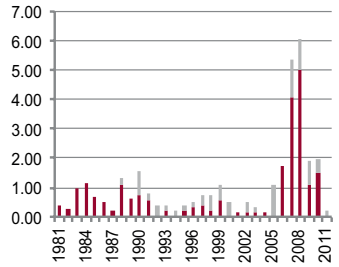
Anorectal atresia/stenosis



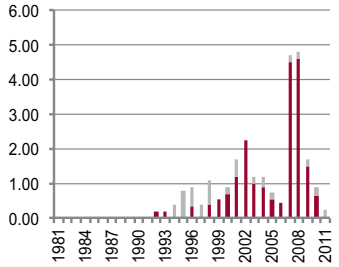
Hypospadias



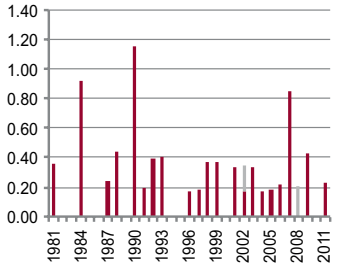
Renal agenesis



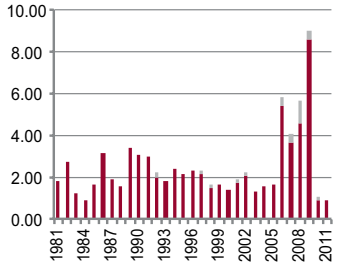
Cystic kidney



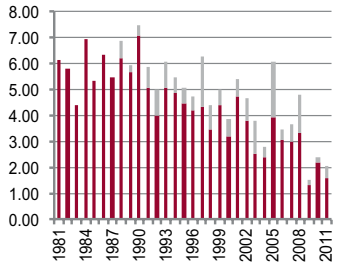
Bladder exstrophy



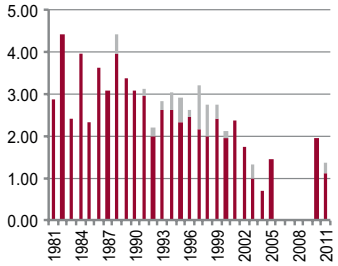
Polydactyly, preaxial



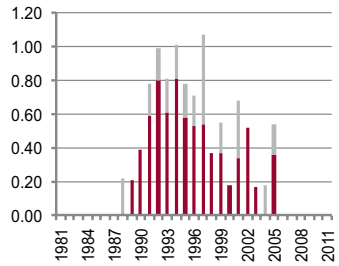
Limb reduction defects



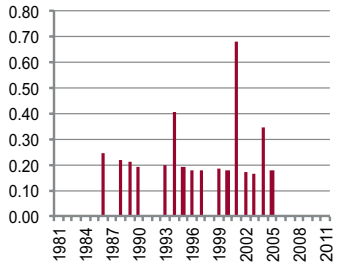
Limb reduction defects - transverse



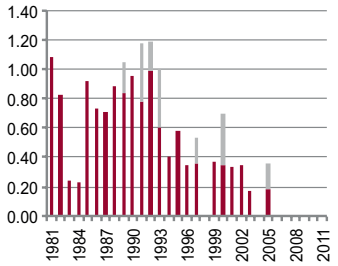
Limb reduction defects - preaxial



Limb reduction defects - postaxial



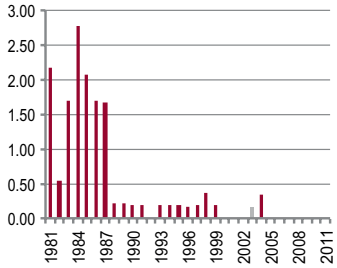
Limb reduction defects - intercalary



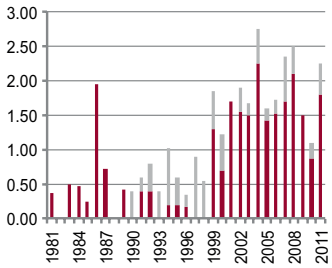
Note: L+S rates, ToP rates

Italy-North East

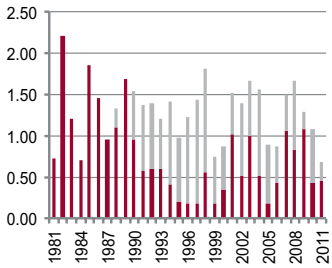
Limb reduction defects - mixed



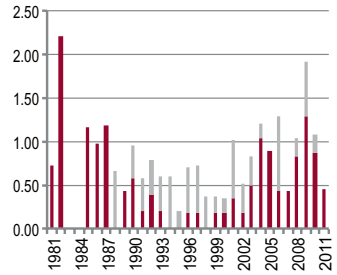
Diaphragmatic hernia



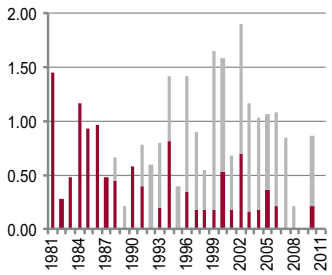
Omphalocele



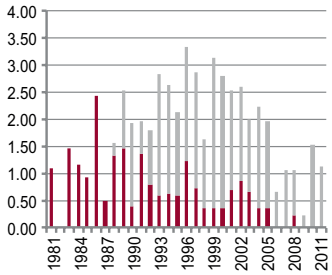
Gastroschisis



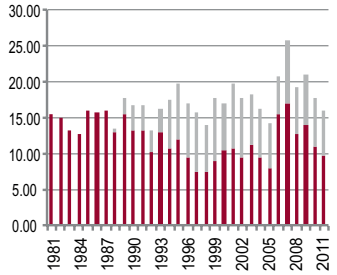
Trisomy 13



Trisomy 18



Down Syndrome



Note: L+S rates, ToP rates

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 million inhabitants and 30,000 births per 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, paediatric cardiology departments, paediatric cardiac surgery units, prenatal diagnostic centres and medical genetics units.
Cytogenetic laboratories only confirm karyotype for cases already known. Mothers are interviewed by using a standardised questionnaire. Malformed babies diagnosed within the first year of life are also registered.

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

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

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E-mail: apier@ifc.cnr.it
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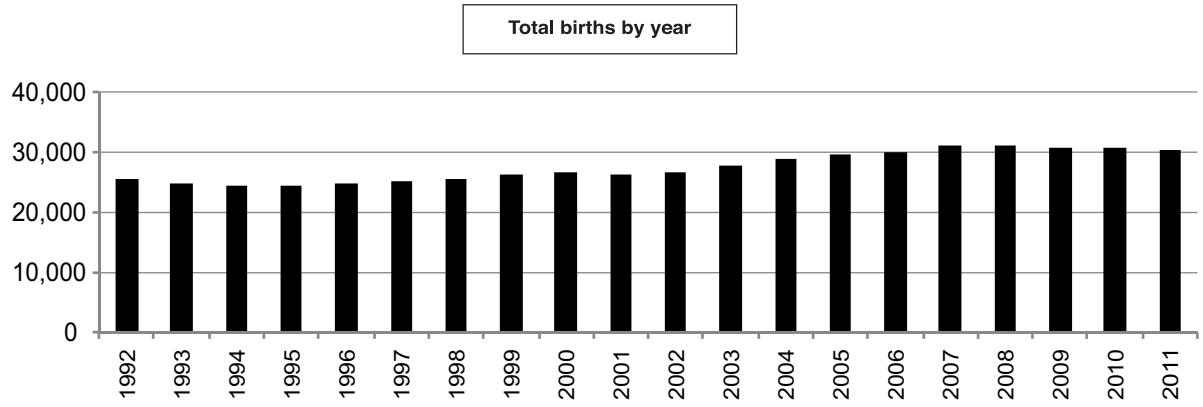
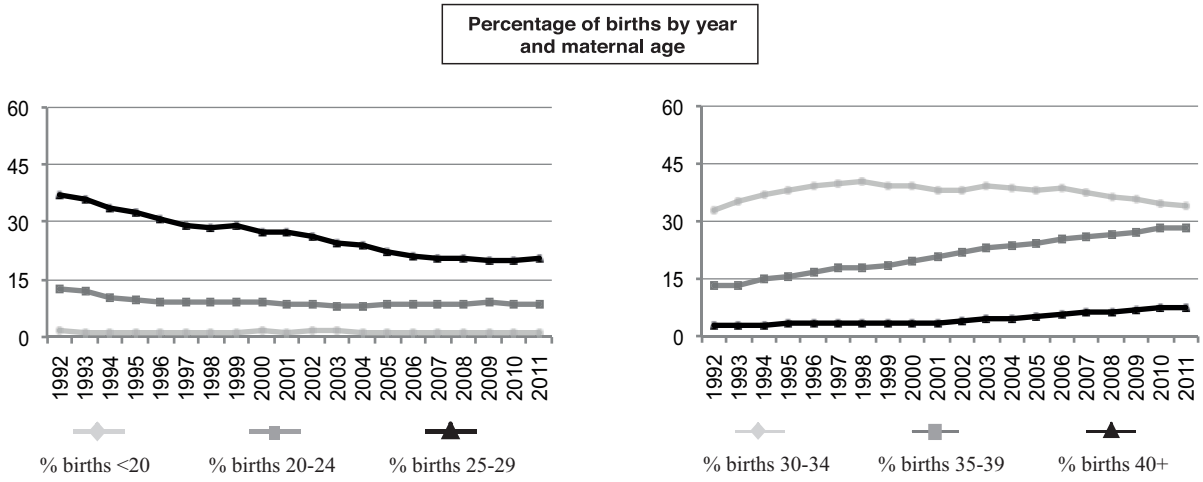
Italy-Tuscany: RTDC





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	15	100.0	Cystic kidney	7	17.9
Spina bifida	29	78.4	Limb reduction defects	11	27.5
Encephalocele	2	22.2	Diaphragmatic hernia	5	21.7
Holoprosencephaly	10	83.3	Omphalocele	15	83.3
Hydrocephaly	15	42.9	Gastroschisis	3	33.3
Hypoplastic left heart syndrome	18	64.3	Trisomy 13	15	93.8
Cleft palate without cleft lip	1	3.6	Trisomy 18	46	92.0
Cleft lip with or without cleft palate	11	22.0	Down syndrome	169	72.8
Renal agenesis	5	71.4			

Total ToPs with births defects = 487 (Ratio ToPs/Births: 5.32 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy-Tuscany: RTDC, 2011

Live births (LB)	30,098
Stillbirths (SB)	83
Total births	30,181
Number of terminations of pregnancy (ToP) for birth defects	175

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	6	1.99
Spina bifida	4	0	13	5.63
Encephalocele	1	0	2	0.99
Microcephaly	1	0	0	0.33
Holoprosencephaly	0	0	3	0.99
Hydrocephaly	3	2	8	4.31
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	1	0.33
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	3	0	0	0.99
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	1	2.65
Tetralogy of Fallot	4	1	1	1.99
Hypoplastic left heart syndrome	2	1	4	2.32
Coarctation of aorta	4	1	0	1.66
Choanal atresia, bilateral	1	0	0	0.33
Cleft palate without cleft lip	9	0	1	3.31
Cleft lip with or without cleft palate	6	0	3	2.98
Oesophageal atresia/stenosis with or without fistula	4	0	0	1.33
Small intestine atresia/stenosis	4	0	0	1.33
Anorectal atresia/stenosis	1	0	1	0.66
Undescended testis (36 weeks of gestation or later)	22	0	0	7.29
Hypospadias	46	0	1	15.57
Epispadias	0	0	0	0.00
Indeterminate sex	1	1	2	1.33
Renal agenesis	1	0	3	1.33
Cystic kidney	6	1	3	3.31
Bladder exstrophy	0	1	0	0.33
Polydactyly, preaxial	3	0	0	0.99
Total Limb reduction defects (include unspecified)	8	1	4	4.31
Transverse	8	0	3	3.64
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	0	1	1	0.66
Diaphragmatic hernia	4	0	1	1.66
Omphalocele	1	0	5	1.99
Gastroschisis	5	0	0	1.66
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.33
Trisomy 13	0	0	4	1.33
Trisomy 18	1	1	15	5.63
Down syndrome, all ages (include age unknown)	21	0	57	25.84
<20	0	0	0	0.00
20-24	1	0	0	3.77
25-29	3	0	3	9.79
30-34	7	0	9	15.72
35-39	4	0	25	34.04
40-44	6	0	19	117.43
45+	0	0	1	60.61
unknown	0	0	0	---

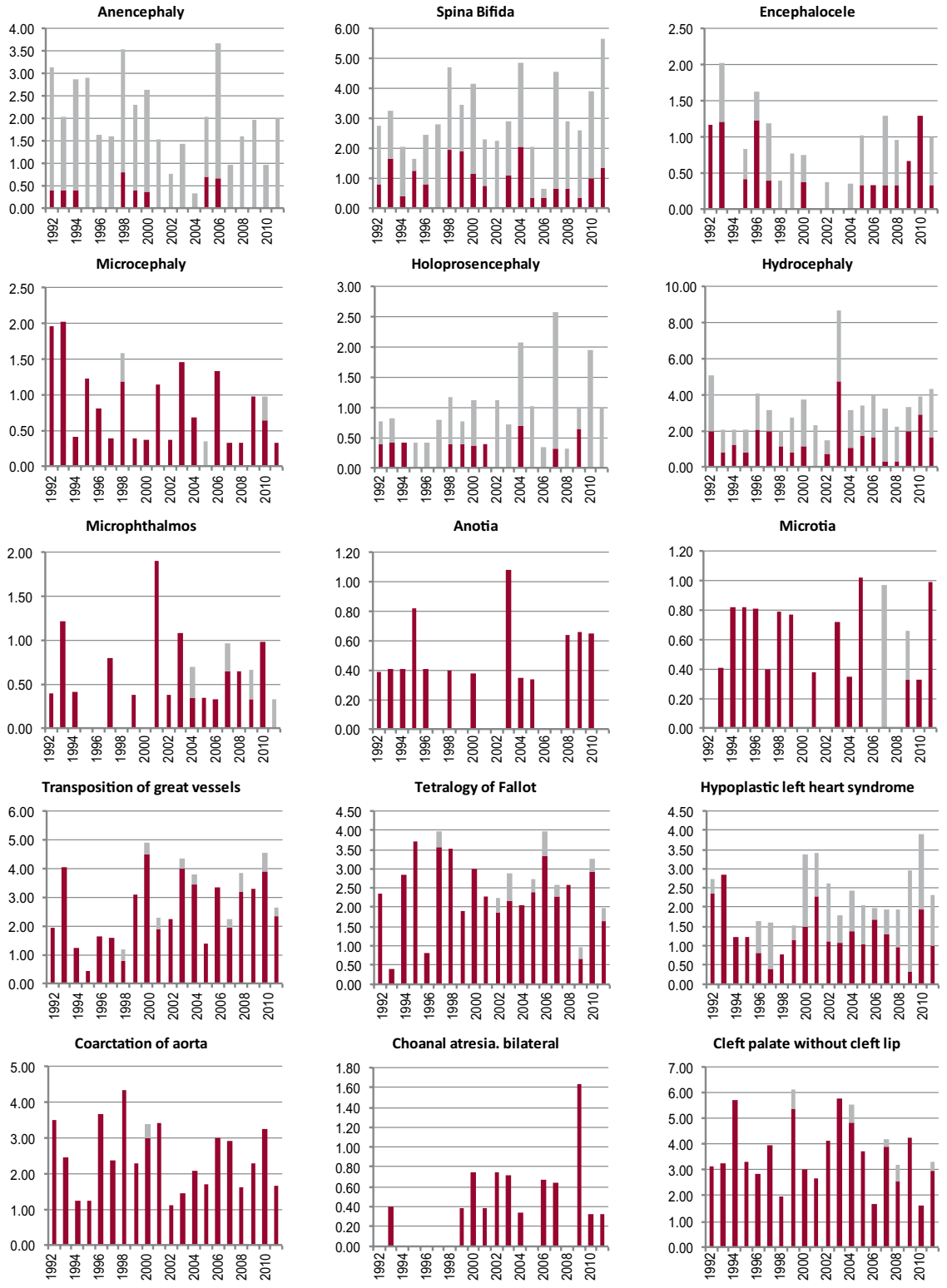
Italy-Tuscany: RTDC, Previous years rates 1992 - 2011

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

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births					**123,738**	**129,710**	**142,822**	**153,650**
Anencephaly					2.51	2.31	1.68	1.50
Spina bifida					2.42	3.47	2.52	3.90
Encephalocele					1.13	0.62	0.42	1.04
Microcephaly					1.29	0.77	0.84	0.59
Holoprosencephaly					0.57	0.85	1.05	1.37
Hydrocephaly					3.07	2.78	4.13	3.38
Anophthalmos					0.00	0.23	0.21	0.00
Microphthalmos					0.40	0.62	0.56	0.72
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.07	0.00
Anotia					0.48	0.15	0.35	0.39
Microtia					0.57	0.46	0.42	0.59
Unspecified Anotia/Microtia					0.00	0.00	0.00	0.00
Transposition of great vessels					1.86	2.62	3.01	3.32
Tetralogy of Fallot					2.02	2.93	2.80	2.28
Hypoplastic left heart syndrome					1.94	2.16	2.17	2.60
Coarctation of aorta					2.42	3.16	1.89	2.34
Choanal atresia, bilateral					0.08	0.31	0.49	0.59
Cleft palate without cleft lip					3.64	3.55	4.13	3.32
Cleft lip with or without cleft palate					6.79	7.17	5.32	5.21
Oesophageal atresia/stenosis with or without fistula					2.26	2.47	2.31	2.21
Small intestine atresia/stenosis					0.97	0.46	1.40	1.30
Anorectal atresia/stenosis					1.54	2.54	2.38	1.95
Undescended testis (36 weeks of gestation or later)					3.80	8.87	7.35	6.64
Hypospadias					4.93	3.85	7.21	13.93
Epispadias					0.24	0.23	0.28	0.13
Indeterminate sex					0.89	0.62	0.42	0.91
Renal agenesis					1.62	1.31	0.70	0.98
Cystic kidney					3.23	3.39	4.69	4.04
Bladder exstrophy					0.32	0.15	0.14	0.33
Polydactyly, preaxial					0.81	1.31	0.91	1.11
Total Limb reduction defects (include unspecified)					5.41	5.32	5.39	4.23
Transverse					3.96	2.85	3.15	3.25
Preaxial					0.24	0.46	0.56	0.52
Postaxial					0.16	0.39	0.21	0.26
Intercalary					0.24	0.77	0.42	0.07
Mixed					0.48	0.46	0.00	0.07
Unspecified					0.00	0.23	1.47	0.46
Diaphragmatic hernia					1.37	2.00	1.75	2.15
Omphalocele					2.02	1.46	1.54	2.21
Gastroschisis					0.40	0.46	0.77	1.04
Unspecified Omphalocele/Gastroschisis					0.32	0.46	0.00	0.13
Prune belly sequence					0.16	0.08	0.00	0.26
Trisomy 13					0.65	0.85	1.47	1.69
Trisomy 18					2.67	3.08	2.87	5.08
Down syndrome, all ages (include age unknown)					14.87	16.27	16.31	21.74
<20					0.00	0.00	0.00	10.67
20-24					7.70	3.49	5.08	6.70
25-29					9.24	6.60	3.01	7.06
30-34					12.76	12.13	6.40	9.52
35-39					27.07	28.08	26.57	32.47
40-44					76.34	125.28	124.94	97.17
45+					182.65	0.00	183.49	159.86
unknown					---	---	---	---

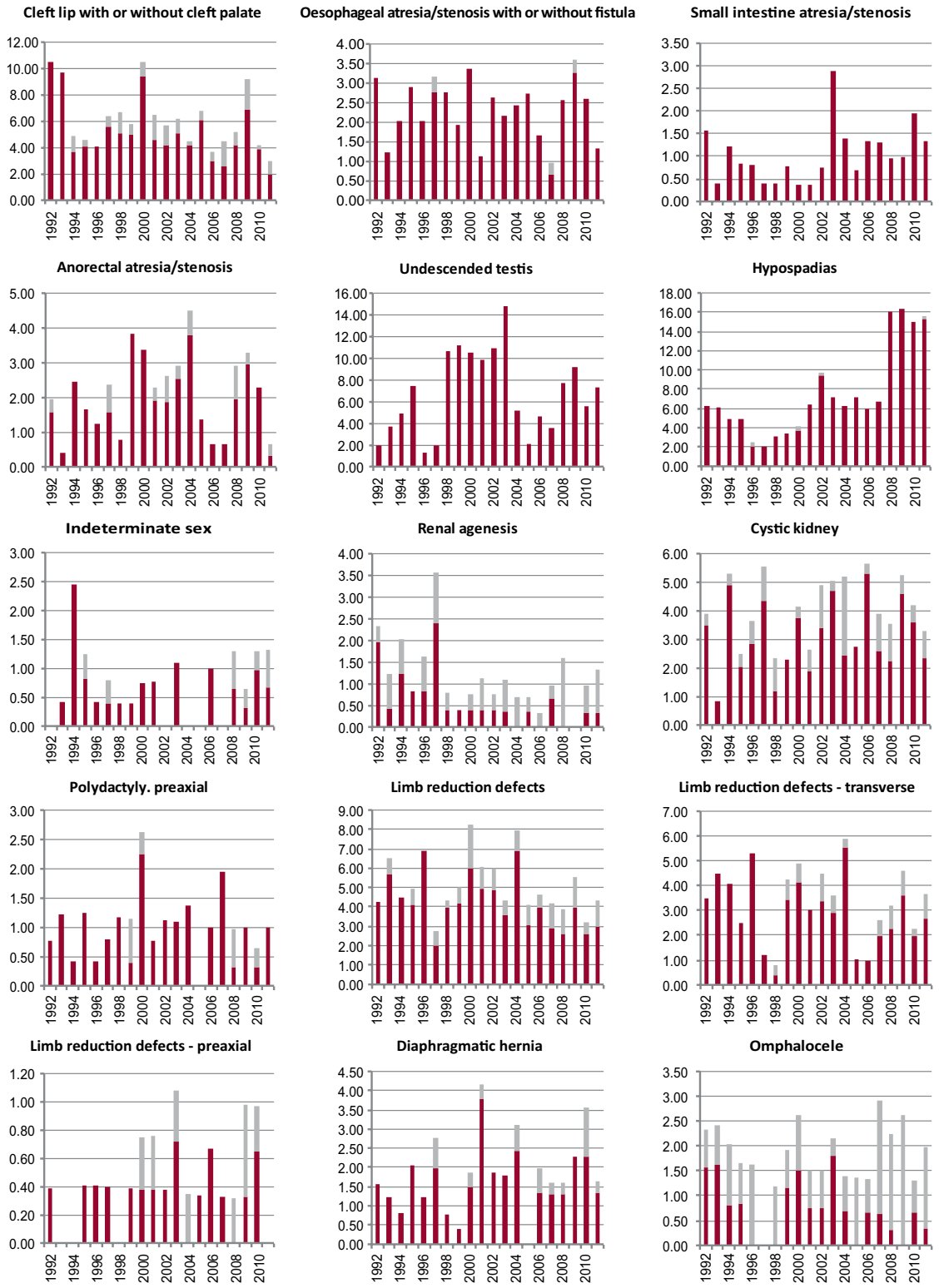
Italy-Tuscany: RTDC

Time trends 1992-2011 (Birth prevalence rates per 10,000)



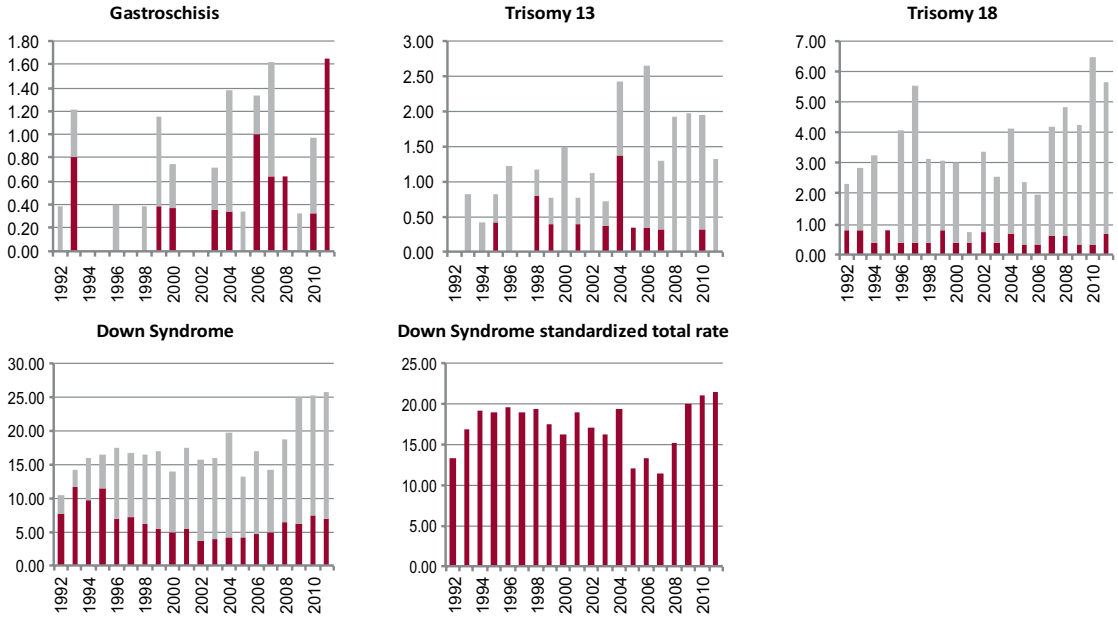
Note: L+S rates, ToP rates

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.

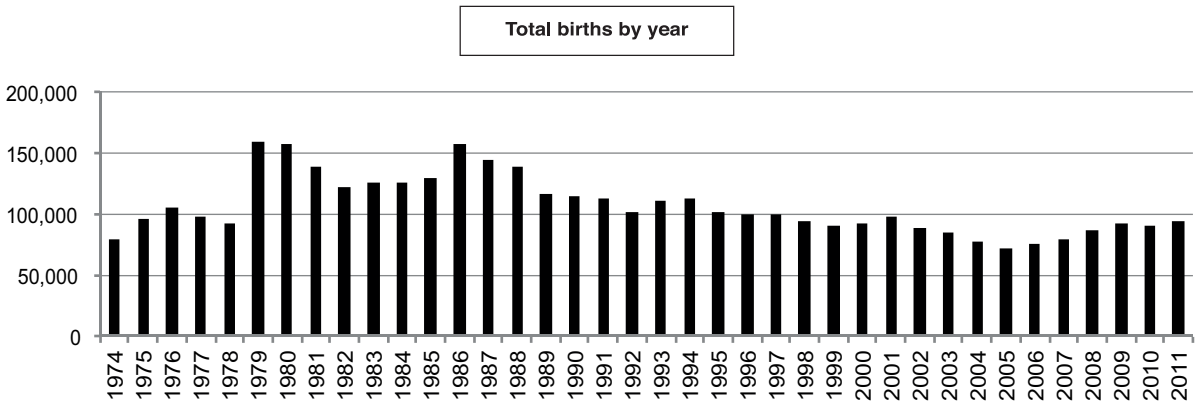
Sources of ascertainment:
Reports are obtained from delivery units and pediatric clinics of the participating hospitals.

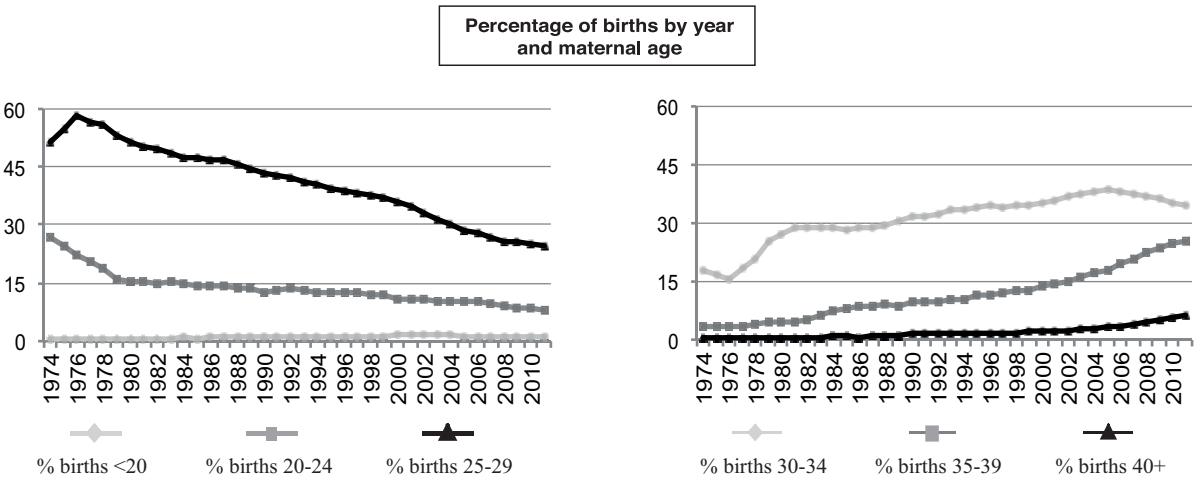
Exposure information:
Exposure to drugs, X-ray and viral infections are available.

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 1975 1976 1977 1978 1979 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 2011


Percentage of births by year and maternal age
60
45
30
15
0
1974 1976 1978 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+

Japan: JAOG, 2011

Live births (LB)	7,601
Stillbirths (SB)	36
Total births	94,767
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	1	nr	0.32
Spina bifida	50	3	nr	5.59
Encephalocele	3	0	nr	0.32
Microcephaly	11	0	nr	1.16
Holoprosencephaly	8	2	nr	1.06
Hydrocephaly	71	3	nr	7.81
Anophthalmos	0	0	nr	0.00
Microphthalmos	5	0	nr	0.53
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	18	7	nr	2.64
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	40	3	nr	4.54
Tetralogy of Fallot	81	1	nr	8.65
Hypoplastic left heart syndrome	45	6	nr	5.38
Coarctation of aorta	69	2	nr	7.49
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	49	1	nr	5.28
Cleft lip with or without cleft palate	205	12	nr	22.90
Oesophageal atresia/stenosis with or without fistula	47	7	nr	5.70
Small intestine atresia/stenosis	79	3	nr	8.65
Anorectal atresia/stenosis	67	2	nr	7.28
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	53	0	nr	5.59
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	27	7	nr	3.59
Cystic kidney	49	5	nr	5.70
Bladder exstrophy	2	0	nr	0.21
Polydactyly, preaxial	77	4	nr	8.55
Total Limb reduction defects (include unspecified)	24	4	nr	2.95
Transverse	2	1	nr	0.32
Preaxial	4	2	nr	0.63
Postaxial	0	0	nr	0.00
Intercalary	4	0	nr	0.42
Mixed	8	0	nr	0.84
Unspecified	6	1	nr	0.74
Diaphragmatic hernia	68	12	nr	8.44
Omphalocele	27	4	nr	3.27
Gastroschisis	18	4	nr	2.32
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13	15	5	nr	2.11
Trisomy 18	61	37	nr	10.34
Down syndrome, all ages (include age unknown)	141	5	nr	15.41
<20	0	0	nr	0.00
20-24	5	0	nr	6.67
25-29	12	1	nr	5.56
30-34	27	2	nr	8.83
35-39	65	2	nr	27.82
40+	32	0	nr	55.17
unknown	0	0	nr	---

nr = data not reported or not available

Japan: JAOG, Previous years rates 1974 - 2011

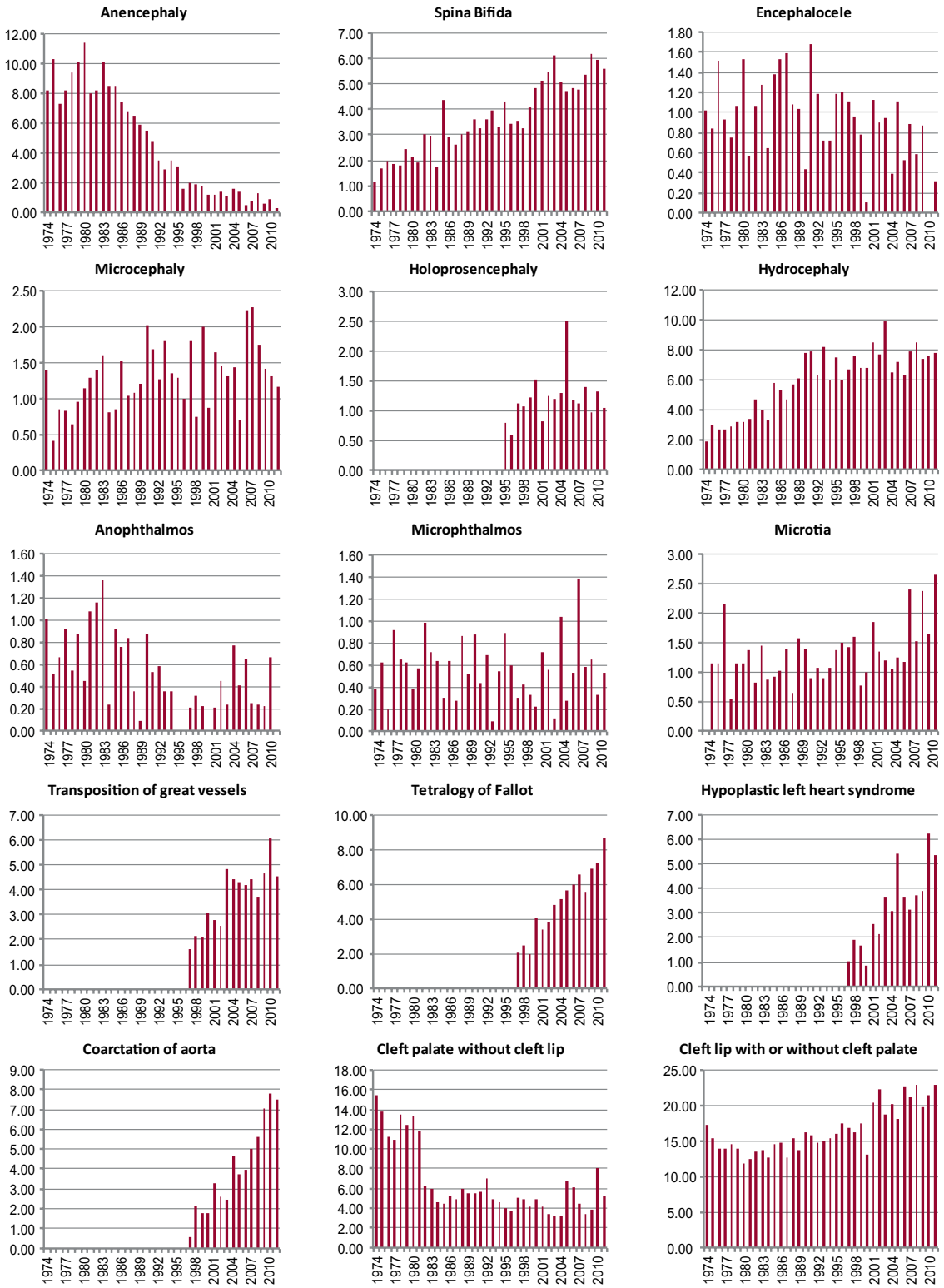
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**280,942**	**645,820**	**659,696**	**625,335**	**525,703**	**472,208**	**399,683**	**443,548**
Anencephaly	8.58	9.55	8.47	5.96	2.93	1.63	1.18	0.74
Spina bifida	1.64	2.09	3.02	3.10	3.73	4.17	5.28	5.59
Encephalocele	1.14	1.01	1.20	1.18	0.99	0.83	0.78	0.52
Microcephaly	0.85	1.01	1.24	1.38	1.35	1.42	1.43	1.56
Holoprosencephaly	nr	nr	nr	nr	0.70*	1.14	1.45	1.17
Hydrocephaly	2.56	3.08	4.64	6.28	6.81	7.28	7.58	7.82
Anophthalmos	0.71	0.77	0.88	0.54	0.27	0.19	0.50	0.27
Microphthalmos	0.39	0.60	0.65	0.59	0.55	0.40	0.50	0.68
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	nr	nr	0.00*	0.00*
Microtia	0.82	1.25	1.02	1.17	1.18	1.33	1.20	2.12
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	0.00*	0.00*
Transposition of great vessels	nr	nr	nr	nr	nr	2.33	4.03	4.69
Tetralogy of Fallot	nr	nr	nr	nr	nr	2.77	5.05	7.03
Hypoplastic left heart syndrome	nr	nr	nr	nr	nr	1.61	3.53	4.53
Coarctation of aorta	nr	nr	nr	nr	nr	1.91	3.43	6.65
Choanal atresia, bilateral	nr	nr	nr	nr	nr	nr	0.00*	0.02
Cleft palate without cleft lip	13.28	12.46	5.24	5.49	4.87	4.64	4.45	5.05
Cleft lip with or without cleft palate	15.31	13.19	13.93	14.68	15.67	16.88	20.42	21.67
Oesophageal atresia/stenosis with or without fistula	nr	1.20*	1.20	1.70	2.40	3.60	4.58	4.98
Small intestine atresia/stenosis	nr	nr	nr	nr	nr	4.62	6.93	7.82
Anorectal atresia/stenosis	3.84	3.92	3.97	4.17	4.24	4.60	5.98	6.83
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr	nr
Hypospadias	1.46	2.12	2.40	2.53	2.87	3.43	4.23	5.19
Epispadias	nr	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr	nr	nr	nr	nr
Renal agenesis	nr	nr	nr	1.22*	1.46	1.78	2.33	2.91
Cystic kidney	nr	nr	nr	nr	nr	3.18	4.60	4.53
Bladder exstrophy	0.10	0.20*	0.14	0.14	0.08	0.30	0.23	0.29
Polydactyly, preaxial	nr	nr	nr	5.89*	6.79	5.93	6.71	6.74
Total Limb reduction defects (include unspecified)	nr	nr	nr	nr	3.37*	3.22	3.58	3.81
Transverse	nr	nr	nr	nr	0.33*	0.38	0.33	0.29
Preaxial	nr	nr	nr	nr	0.54*	0.59	0.60	0.90
Postaxial	nr	nr	nr	nr	0.26*	0.30	0.45	0.25
Intercalary	nr	nr	nr	nr	1.41*	0.78	0.73	1.04
Mixed	nr	nr	nr	nr	0.57*	0.68	1.00	0.90
Unspecified	nr	nr	nr	nr	0.26*	0.49	0.48	0.43
Diaphragmatic hernia	nr	nr	nr	2.39*	2.95	5.15	6.03	6.67
Omphalocele	0.85	1.22	1.76	3.26	2.85	3.43	3.73	3.86
Gastroschisis	0.96	1.01	1.02	1.26	1.48	2.39	2.65	2.50
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.21	0.30	0.28	0.25	0.23
Prune belly sequence	nr	nr	nr	nr	0.10*	0.02	0.00	0.09
Trisomy 13	nr	nr	nr	nr	0.61*	1.00	1.68	2.03
Trisomy 18	nr	nr	nr	nr	2.65*	4.72	8.18	9.90
Down syndrome, all ages (include age unknown)	nr	4.25*	5.24	5.95	6.60	8.68	10.88	13.19
<20	nr	nr	nr	nr	4.39*	4.56	5.01	3.65
20-24	nr	nr	nr	nr	2.58*	2.90	4.11	3.60
25-29	nr	nr	nr	nr	4.26*	5.19	5.44	5.74
30-34	nr	nr	nr	nr	5.85*	8.11	9.49	8.07
35-39	nr	nr	nr	nr	15.76*	18.95	21.46	24.34
40+	nr	nr	nr	nr	60.67*	52.33	50.35	49.77
unknown	---	---	---	---	---	---	---	---

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

Japan: JAOG

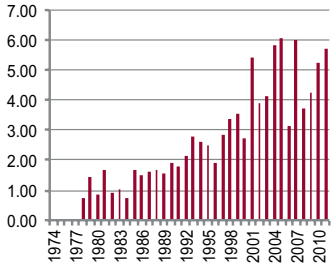
Time trends 1974-2011 (Birth prevalence rates per 10,000)



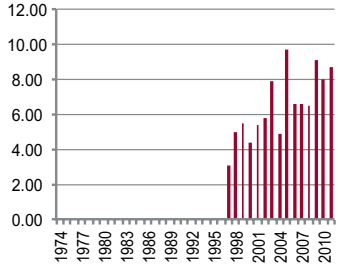
Note: L+S rates

Japan: JAOG

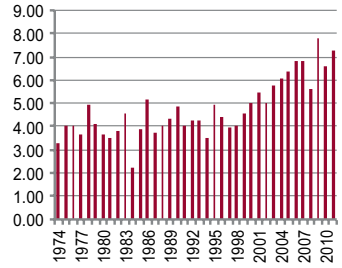
Oesophageal atresia/stenosis with or without fistula



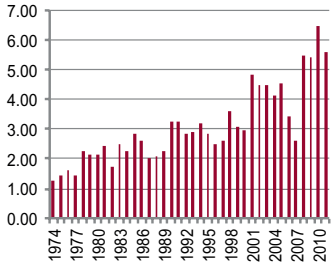
Small intestine atresia/stenosis



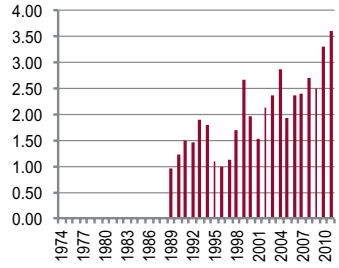
Anorectal atresia/stenosis



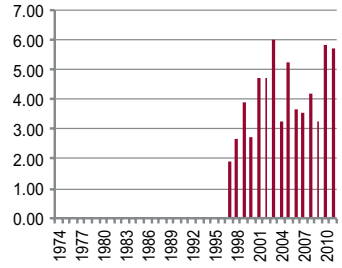
Hypospadias



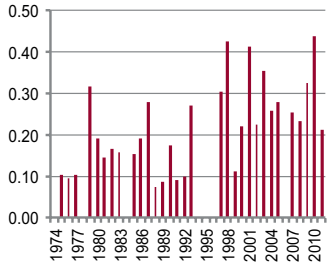
Renal agenesis



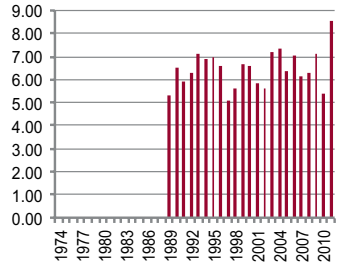
Cystic kidney



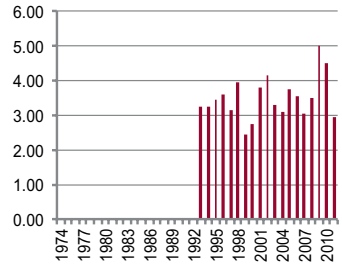
Bladder exstrophy



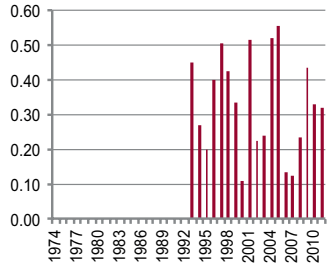
Polydactyly, preaxial



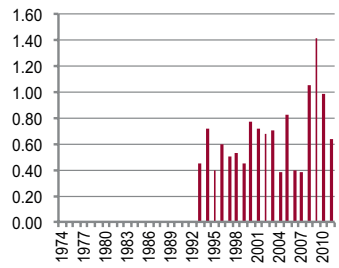
Limb reduction defects



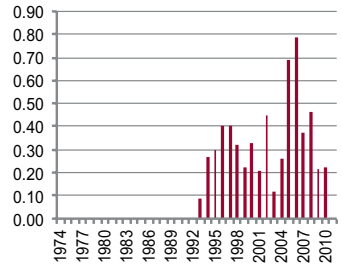
Limb reduction defects - transverse



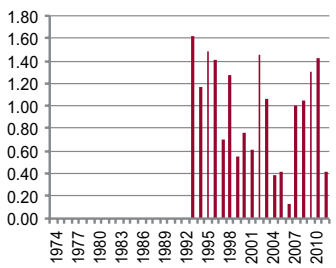
Limb reduction defects - preaxial



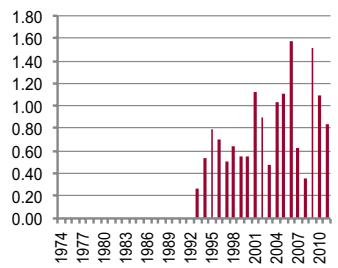
Limb reduction defects - postaxial



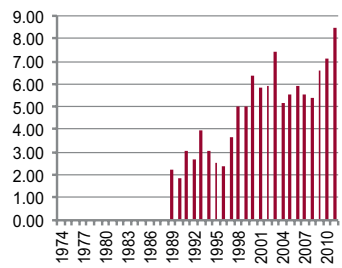
Limb reduction defects - intercalary



Limb reduction defects - mixed

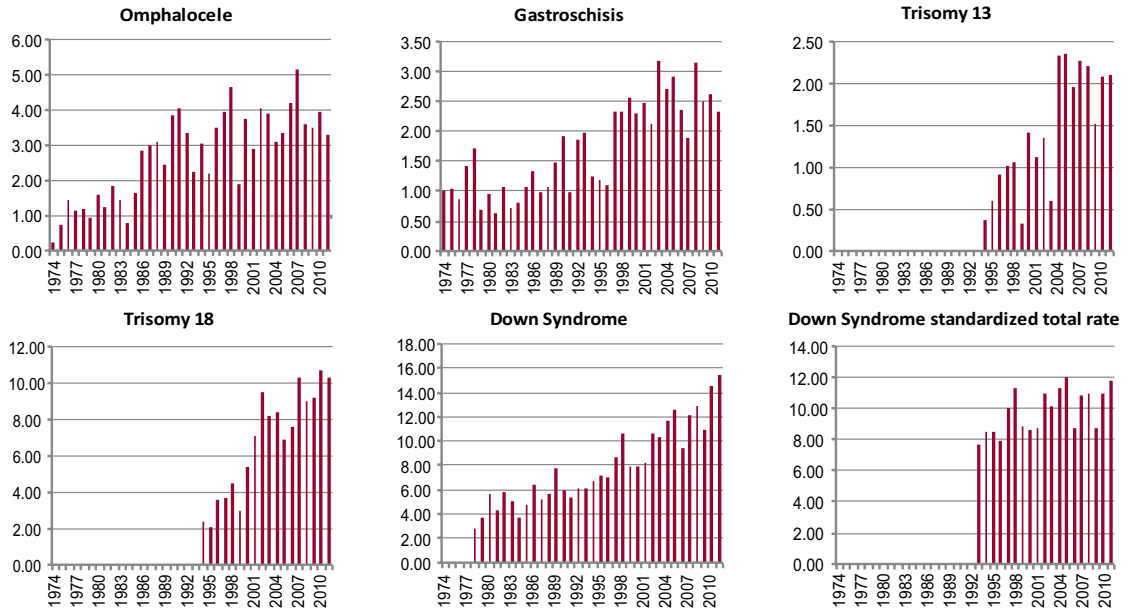


Diaphragmatic hernia



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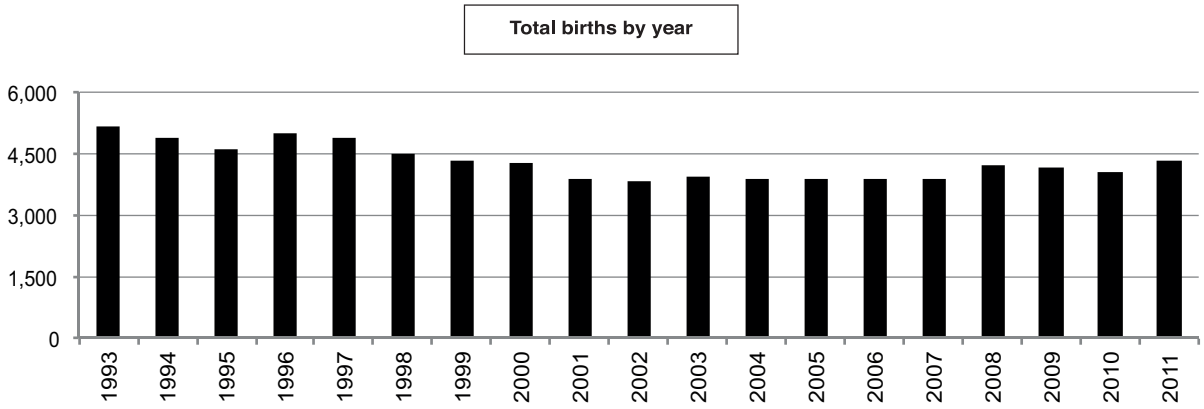
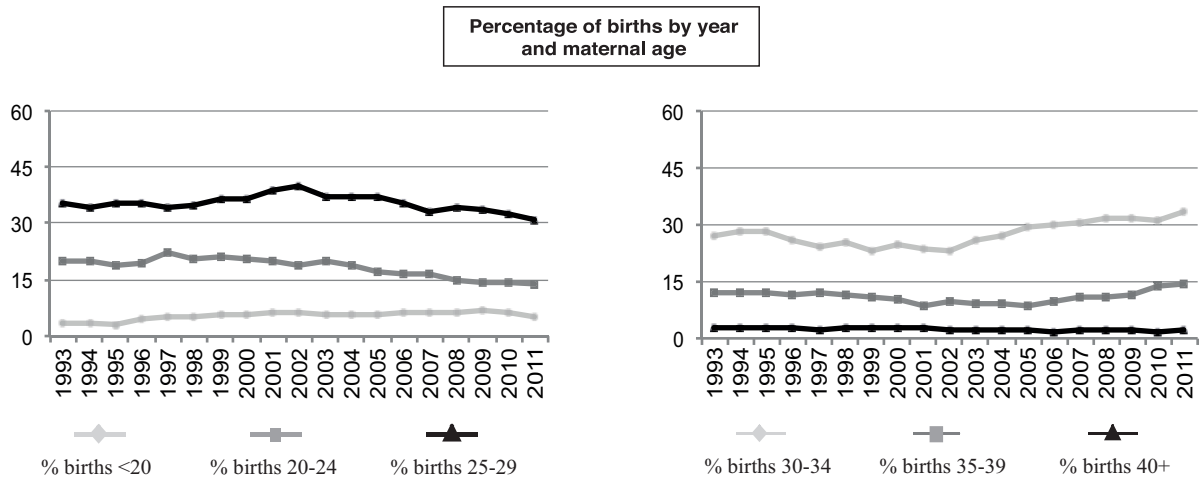
Malta Congenital Anomalies Registry
Department of Health Information and Research
95, Guardamangia Hill
Guardamangia PTA 1313, Malta
Phone: 356 25599000
Fax: 356 25599385
E-mail: miriam.gatt@gov.mt

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
2011


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, 2011

Live births (LB)	4,283
Stillbirths (SB)	28
Total births	4,311
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	2	1		6.96
Spina bifida	1	0		2.32
Encephalocele	0	0		0.00
Microcephaly	2	0		4.64
Holoprosencephaly	0	0		0.00
Hydrocephaly	0	0		0.00
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	2	1		6.96
Tetralogy of Fallot	1	0		2.32
Hypoplastic left heart syndrome	1	0		2.32
Coarctation of aorta	1	0		2.32
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	1	0		2.32
Cleft lip with or without cleft palate	4	0		9.28
Oesophageal atresia/stenosis with or without fistula	3	0		6.96
Small intestine atresia/stenosis	1	1		4.64
Anorectal atresia/stenosis	0	0		0.00
Undescended testis (36 weeks of gestation or later)	0	0		0.00
Hypospadias	17	0		39.43
Epispadias	0	0		0.00
Indeterminate sex	0	0		0.00
Renal agenesis	0	0		0.00
Cystic kidney	1	0		2.32
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	4	0		9.28
Total Limb reduction defects (include unspecified)	0	0		0.00
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	2	1		6.96
Omphalocele	0	0		0.00
Gastroschisis	1	0		2.32
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	0		2.32
Trisomy 18	1	0		2.32
Down syndrome, all ages (include age unknown)	9	2		25.52
<20	0	0		0.00
20-24	0	1		16.67
25-29	3	0		22.42
30-34	0	0		0.00
35-39	5	1		96.46
40-44	1	0		116.28
45+	0	0		0.00
unknown	0	0		---

nr = data not reported or not available

Malta: MCAR, Previous years rates 1993 - 2011

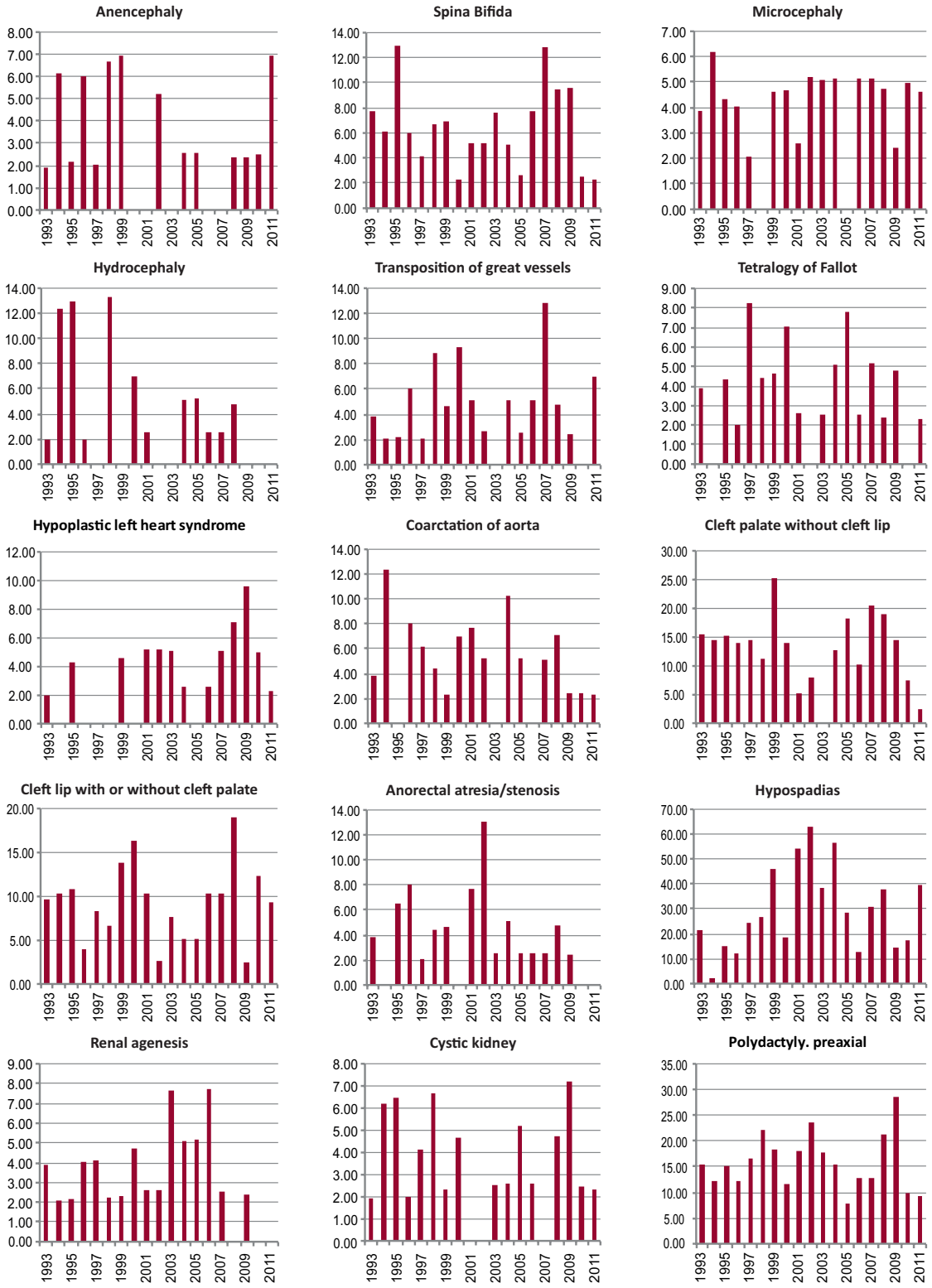
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996*	1997-2001	2002-2006	2007-2011
Total births					**19,646**	**21,869**	**19,404**	**20,653**
Anencephaly					4.07	3.20	2.06	2.91
Spina bifida					8.14	5.03	5.67	7.26
Encephalocele					1.53	2.74	2.06	1.45
Microcephaly					4.58	2.74	4.12	4.36
Holoprosencephaly					0.51	1.83	0.00	0.48
Hydrocephaly					7.13	4.57	2.58	1.45
Anophthalmos					0.51	0.00	0.00	0.00
Microphthalmos					0.51	1.83	0.52	0.48
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					3.56	5.94	3.09	5.33
Tetralogy of Fallot					2.55	5.49	3.61	2.91
Hypoplastic left heart syndrome					1.53	1.83	3.09	5.81
Coarctation of aorta					6.11	5.49	4.12	3.87
Choanal atresia, bilateral					1.02	1.83	1.03	0.00
Cleft palate without cleft lip					14.76	14.18	9.79	12.59
Cleft lip with or without cleft palate					8.65	10.97	6.18	10.65
Oesophageal atresia/stenosis with or without fistula					1.53	1.83	3.09	2.42
Small intestine atresia/stenosis					1.02	1.83	2.06	2.42
Anorectal atresia/stenosis					4.58	3.66	5.15	1.94
Undescended testis (36 weeks of gestation or later)					nr	nr	nr	nr
Hypospadias					12.73	33.38	39.68	28.08
Epispadias					1.53	0.46	0.00	0.00
Indeterminate sex					1.02	1.37	1.55	1.45
Renal agenesis					3.05	3.20	5.67	0.97
Cystic kidney					4.07	3.66	2.58	3.39
Bladder exstrophy					0.00	0.00	0.00	0.00
Polydactyly, preaxial					13.74	17.38	15.46	16.46
Total Limb reduction defects (include unspecified)					6.11	6.86	4.12	6.29
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					5.60	5.03	3.61	7.26
Omphalocele					3.05	1.37	2.06	2.91
Gastroschisis					1.02	1.37	1.03	0.48
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00	0.00
Prune belly sequence					1.02	0.00	0.00	0.00
Trisomy 13					0.00	0.46	0.52	1.94
Trisomy 18					2.04	3.20	5.67	2.91
Down syndrome, all ages (include age unknown)					19.85	15.09	23.19	20.34
<20					0.00	16.74	0.00	15.63
20-24					0.00	0.00	2.82	9.81
25-29					4.34	5.07	9.68	7.37
30-34					20.66	15.16	22.89	15.23
35-39					64.54	51.17	82.69	59.22
40-44					205.34	103.99	229.59	152.28
45+					0.00	588.24	555.56	434.78
unknown					---	---	---	---

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

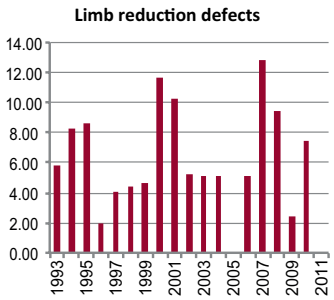
Malta: MCAR

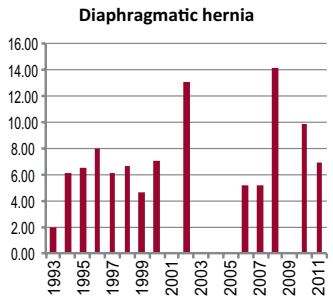
Time trends 1993-2011 (Birth prevalence rates per 10,000)

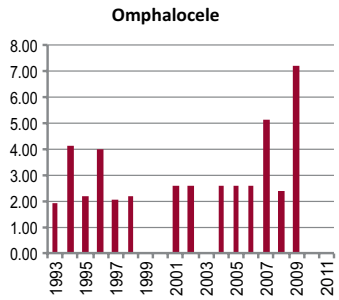


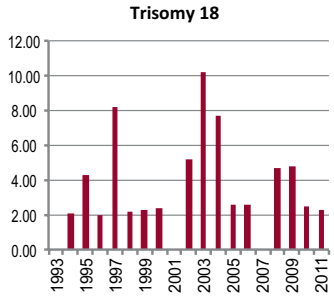
Note: L+S rates

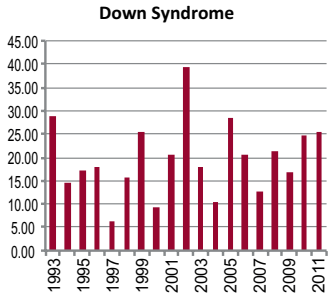
Malta: MCAR

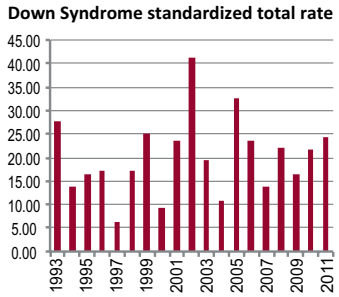












Note: L+S rates

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:
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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)
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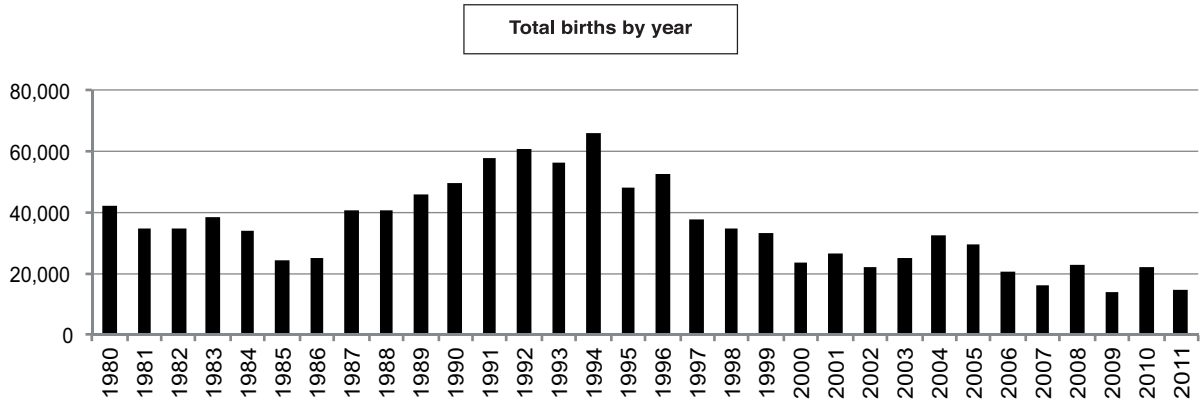
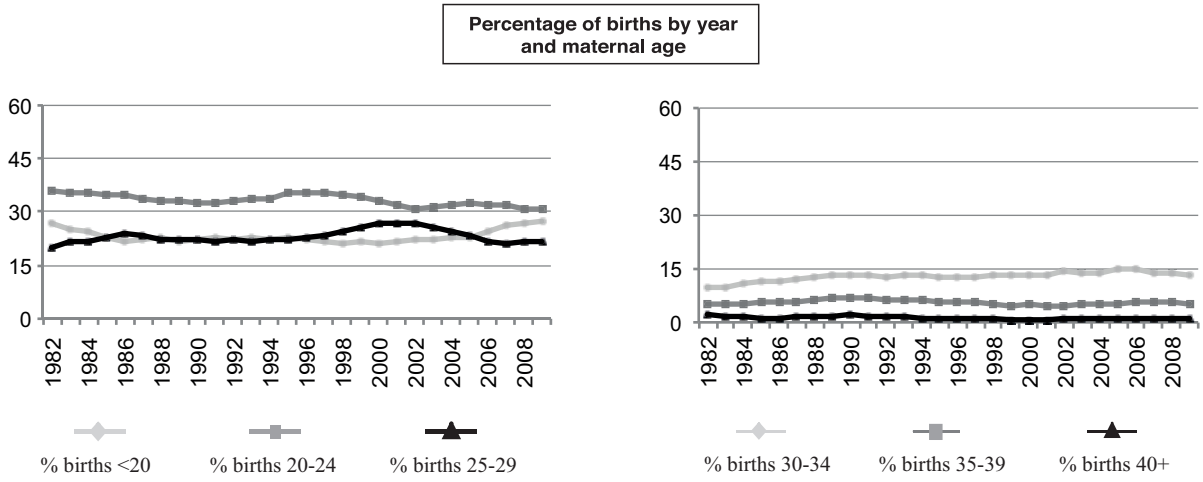
Mexico: RYVEMCE





Mexico: RYVEMCE, 2011

Live births (LB)	14,469
Stillbirths (SB)	260
Total births	14,729
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	0	1		0.68
Spina bifida	5	0		3.39
Encephalocele	0	0		0.00
Microcephaly	3	0		2.04
Holoprosencephaly	1	0		0.68
Hydrocephaly	5	2		4.75
Anophthalmos	nr	nr		nr
Microphthalmos	nr	nr		nr
Unspecified Anophthalmos/Microphthalmos	2	0		1.36
Anotia	nr	nr		nr
Microtia	nr	nr		nr
Unspecified Anotia/Microtia	7	0		4.75
Transposition of great vessels	0	0		0.00
Tetralogy of Fallot	1	0		0.68
Hypoplastic left heart syndrome	0	0		0.00
Coarctation of aorta	1	0		0.68
Choanal atresia, bilateral	1	0		0.68
Cleft palate without cleft lip	3	0		2.04
Cleft lip with or without cleft palate	18	0		12.22
Oesophageal atresia/stenosis with or without fistula	0	0		0.00
Small intestine atresia/stenosis	2	0		1.36
Anorectal atresia/stenosis	1	0		0.68
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	4	0		2.72
Epispadias	0	0		0.00
Indeterminate sex	0	1		0.68
Renal agenesis	0	0		0.00
Cystic kidney	2	0		1.36
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	11	1		8.15
Total Limb reduction defects (include unspecified)	4	0		2.72
Transverse	3	0		2.04
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	0	0		0.00
Mixed	1	0		0.68
Unspecified	0	0		0.00
Diaphragmatic hernia	1	0		0.68
Omphalocele	2	0		1.36
Gastroschisis	8	0		5.43
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	0	0		0.00
Trisomy 18	1	0		0.68
Down syndrome, all ages (include age unknown)	18	0		12.22
<20	4	0		10.20
20-24	3	0		6.15
25-29	0	0		0.00
30-34	1	0		6.54
35-39	6	0		89.55
40+	4	0		416.67
unknown	0	0		---

nr = data not reported or not available

Mexico: RYVEMCE, Previous years rates 1980 - 2011

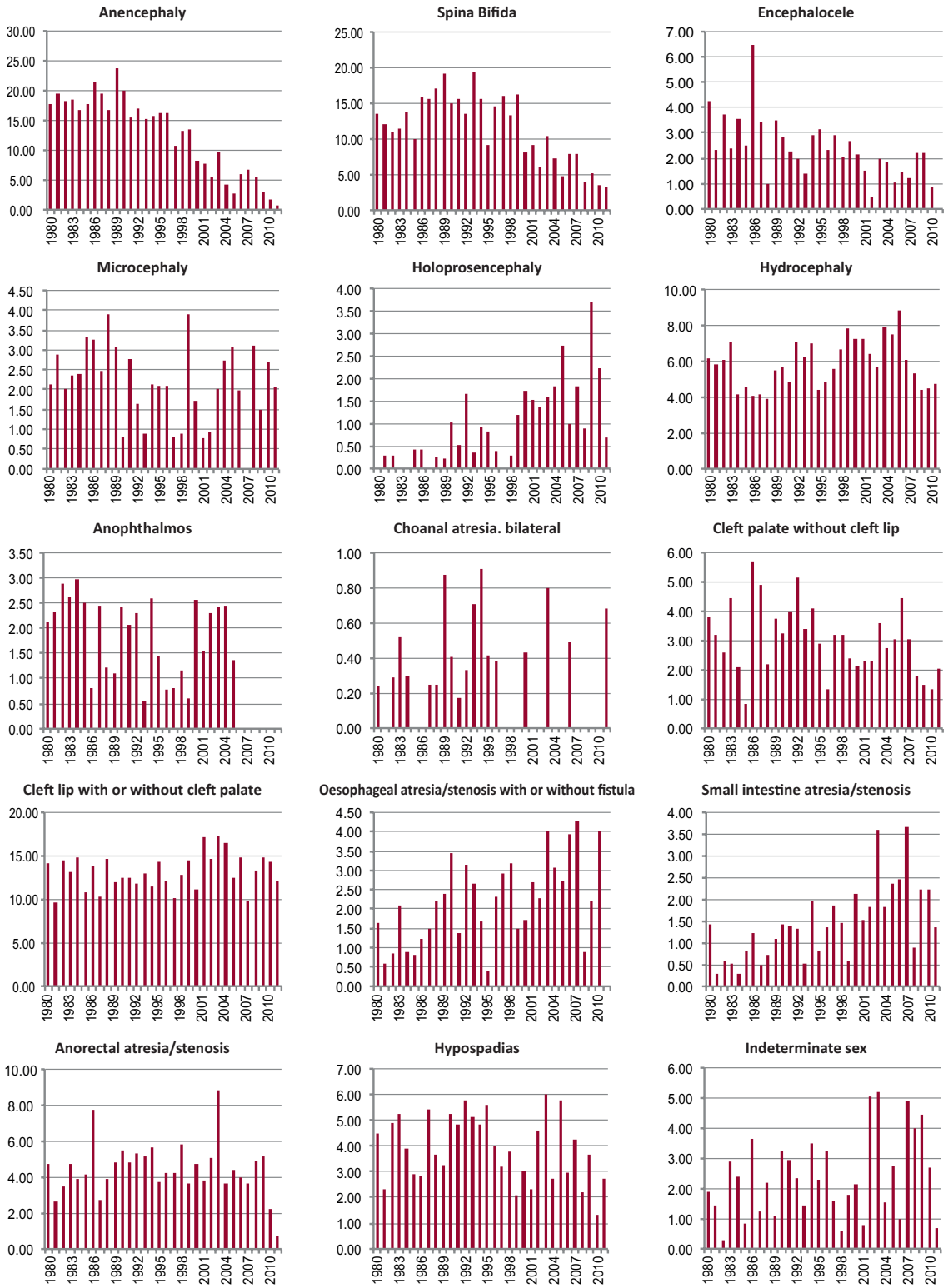
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**76,854**	**155,109**	**234,777**	**282,882**	**154,798**	**129,291**	**89,489**
Anencephaly		18.48	18.44	18.95	16.05	10.98	5.41	3.58
Spina bifida		12.88	12.31	16.48	14.64	13.11	7.19	4.69
Encephalocele		3.38	3.61	2.60	2.33	2.33	1.39	1.34
Microcephaly		2.47	2.58	2.56	1.77	1.62	2.24	2.01
Holoprosencephaly		0.13	0.19	0.43	0.85	0.84	1.78	1.79
Hydrocephaly		5.99	5.35	4.86	6.01	6.85	7.27	5.03
Anophthalmos		2.21	2.45	1.87	1.59	1.23	2.11*	0.00*
Microphthalmos		nr	nr	nr	nr	nr	nr	nr
Unspecified Anophthalmos/Microphthalmos		nr	nr	nr	nr	nr	4.93*	2.23
Anotia		nr	nr	nr	nr	nr	nr	nr
Microtia		nr	nr	nr	nr	nr	nr	nr
Unspecified Anotia/Microtia		6.25	6.83	6.90	5.90	7.36	9.59	9.50
Transposition of great vessels		0.13	0.00	0.13	0.14	0.32	0.31	0.78
Tetralogy of Fallot		0.00	0.00	0.04	0.25	0.19	0.15	0.34
Hypoplastic left heart syndrome		0.00	0.00	0.04	0.00	0.00	0.31	0.22
Coarctation of aorta		0.13	0.00	0.04	0.11	0.00	0.08	0.67
Choanal atresia, bilateral		0.13	0.26	0.38	0.57	0.06	0.23	0.11
Cleft palate without cleft lip		3.51	3.16	3.62	3.46	2.71	3.17	1.90
Cleft lip with or without cleft palate		12.10	13.54	12.39	12.44	12.98	15.16	12.96
Oesophageal atresia/stenosis with or without fistula		1.17	1.22	2.17	2.09	2.45	3.17	2.35
Small intestine atresia/stenosis		0.91	0.64	1.06	1.24	1.49	2.40	2.01
Anorectal atresia/stenosis		3.77	4.64	4.43	4.88	4.46	5.10	3.35
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr	nr
Hypospadias		3.51	4.13	4.51	5.09	2.91	4.41	2.68
Epispadias		nr	nr	nr	nr	nr	0.12*	0.11
Indeterminate sex		1.69	2.00	2.21	2.58	1.36	3.02	3.35
Renal agenesis		0.52	0.19	0.60	0.57	0.45	0.77	1.01
Cystic kidney		0.26	0.32	0.47	0.92	1.42	1.39	1.01
Bladder exstrophy		0.26	0.64	0.38	0.39	0.52	0.15	0.00
Polydactyly, preaxial		11.71	12.06	13.63	12.23	12.02	12.14	9.72
Total Limb reduction defects (include unspecified)		5.20	6.64	6.52	5.94	5.17	6.88	4.69
Transverse		nr	nr	nr	nr	3.63*	3.40	2.46
Preaxial		nr	nr	nr	nr	0.81*	1.31	0.45
Postaxial		nr	nr	nr	nr	0.40*	0.46	0.22
Intercalary		nr	nr	nr	nr	0.40*	0.46	0.34
Mixed		nr	nr	nr	nr	0.61*	0.93	0.89
Unspecified		nr	nr	nr	nr	0.00*	0.31	0.34
Diaphragmatic hernia		0.52	0.45	1.06	1.03	1.03	1.24	1.01
Omphalocele		1.95	1.61	1.36	1.84	1.49	2.32	1.79
Gastroschisis		0.91	0.77	1.45	2.09	3.75	5.34	6.15
Unspecified Omphalocele/Gastroschisis		nr	nr	nr	nr	nr	nr	nr
Prune belly sequence		1.04	1.35	1.32	0.67	0.78	0.54	0.11
Trisomy 13		0.52	0.19	0.34	0.11	0.13	0.70	0.56
Trisomy 18		1.04	0.52	0.47	0.28	0.06	0.62	0.67
Down syndrome, all ages (include age unknown)		14.05	12.12	14.18	13.36	11.37	11.52	13.30
<20		8.05	6.27	11.33	6.76	6.59	7.46	0.54
20-24		7.71	5.10	7.54	7.52	4.10	8.03	0.66
25-29		10.21	5.07	10.12	12.15	5.91	6.02	0.42
30-34		24.84	16.72	15.51	12.80	16.01	8.82	0.49
35-39		52.36	50.44	38.25	39.85	54.23	53.91	2.83
40-44		80.74	197.97	103.51	169.59	308.99	115.29	14.32
45+		75.76	184.33*	177.42*	165.88*	176.99*	123.46*	nr
unknown		---	---	---	---	---	---	---

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

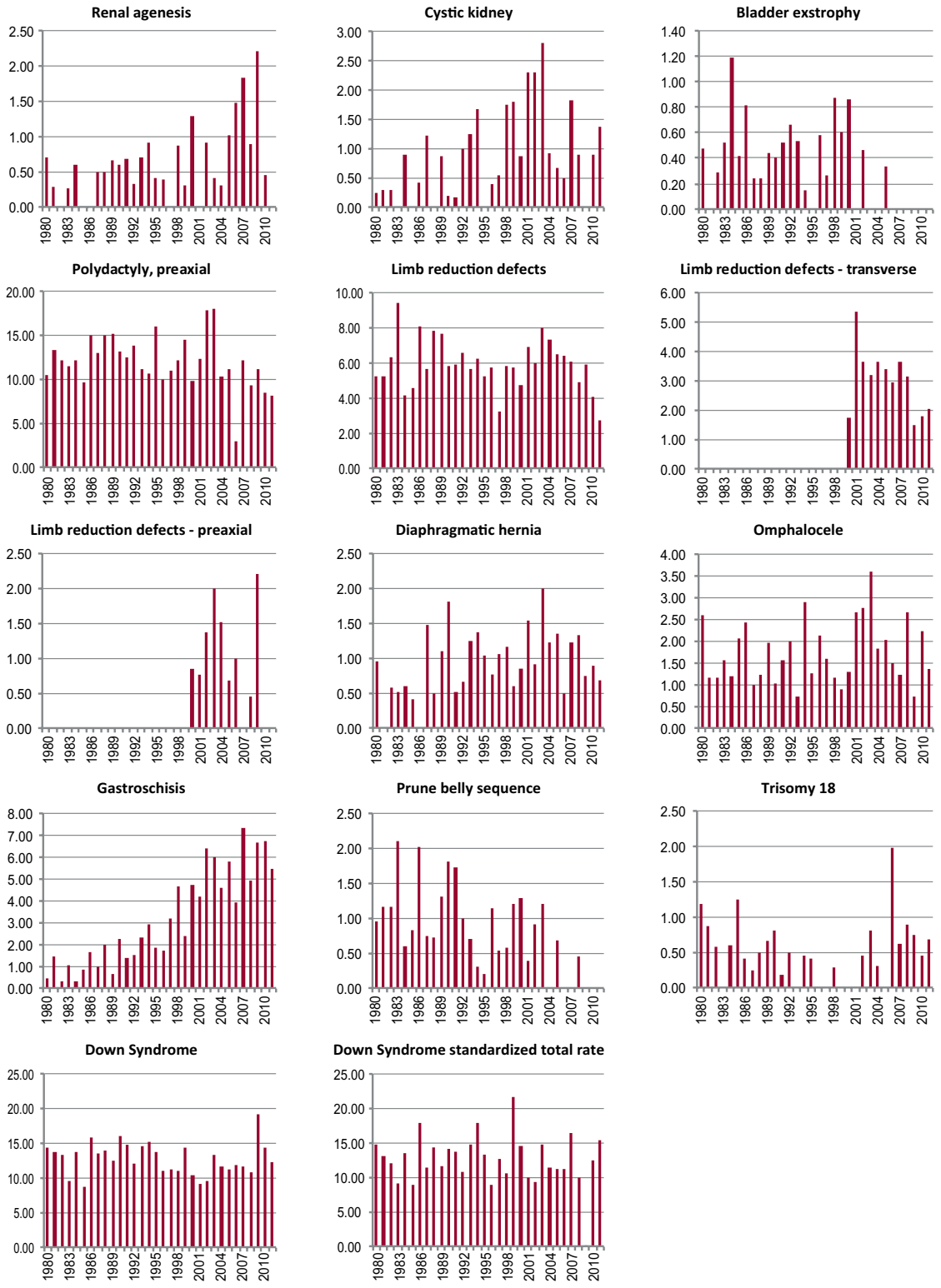
Mexico: RYVEMCE

Time trends 1980-2011 (Birth prevalence rates per 10,000)



Note: L+S rates

Mexico: RYVEMCE



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.

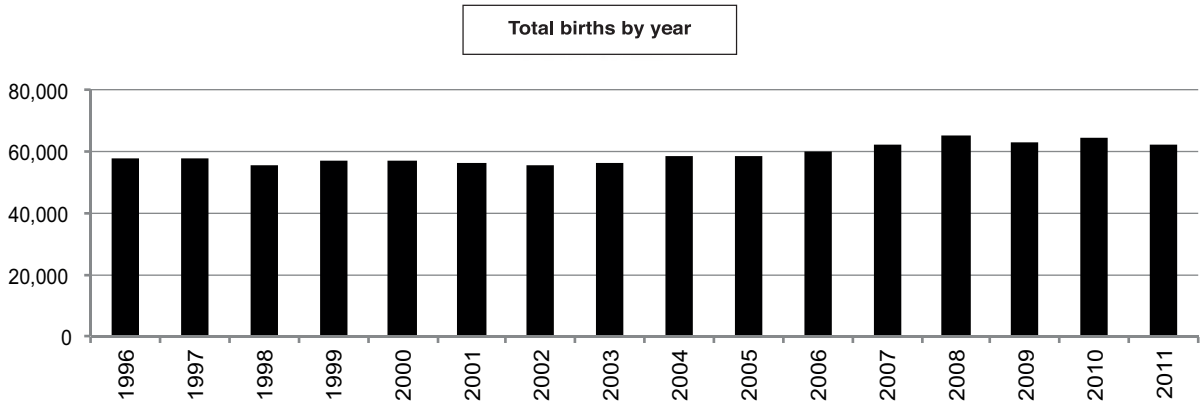
Sources of ascertainment:
Ascertainment is from discharge records of publicly funded hospitals, fetal death notification forms, and terminations of pregnancy.

Exposure information:
Limited exposure information are currently available.

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

Addresses and Staff:
Associate Professor Barry Borman
Director
New Zealand Birth Defects Registry
Centre for Public Health Research
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
2011

New Zealand, 2011

Live births (LB)	61,400
Stillbirths (SB)	420
Total births	61,820
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	nr	nr	0.65
Spina bifida	22	nr	nr	3.56
Encephalocele	3	nr	nr	0.49
Microcephaly	10	nr	nr	1.62
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	15	nr	nr	2.43
Anophthalmos	1	nr	nr	0.16
Microphthalmos	5	nr	nr	0.81
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	5	nr	nr	0.81
Transposition of great vessels	35	nr	nr	5.66
Tetralogy of Fallot	24	nr	nr	3.88
Hypoplastic left heart syndrome	7	nr	nr	1.13
Coarctation of aorta	18	nr	nr	2.91
Choanal atresia, bilateral	4	nr	nr	0.65
Cleft palate without cleft lip	43	nr	nr	6.96
Cleft lip with or without cleft palate	16	nr	nr	2.59
Oesophageal atresia/stenosis with or without fistula	9	nr	nr	1.46
Small intestine atresia/stenosis	16	nr	nr	2.59
Anorectal atresia/stenosis	12	nr	nr	1.94
Undescended testis (36 weeks of gestation or later)	231	nr	nr	37.37
Hypospadias	115	nr	nr	18.60
Epispadias	nr	nr	nr	nr
Indeterminate sex	3	nr	nr	0.49
Renal agenesis	17	nr	nr	2.75
Cystic kidney	16	nr	nr	2.59
Bladder exstrophy	1	nr	nr	0.16
Polydactyly, preaxial	57	nr	nr	9.22
Total Limb reduction defects (include unspecified)	12	nr	nr	1.94
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	14	nr	nr	2.26
Omphalocele	nr	nr	nr	nr
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	2	nr	nr	0.32
Trisomy 18	10	nr	nr	1.62
Down syndrome, all ages (include age unknown)	64	nr	nr	10.35
<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 = data not reported or not available

New Zealand, Previous years rates 1980 - 2011

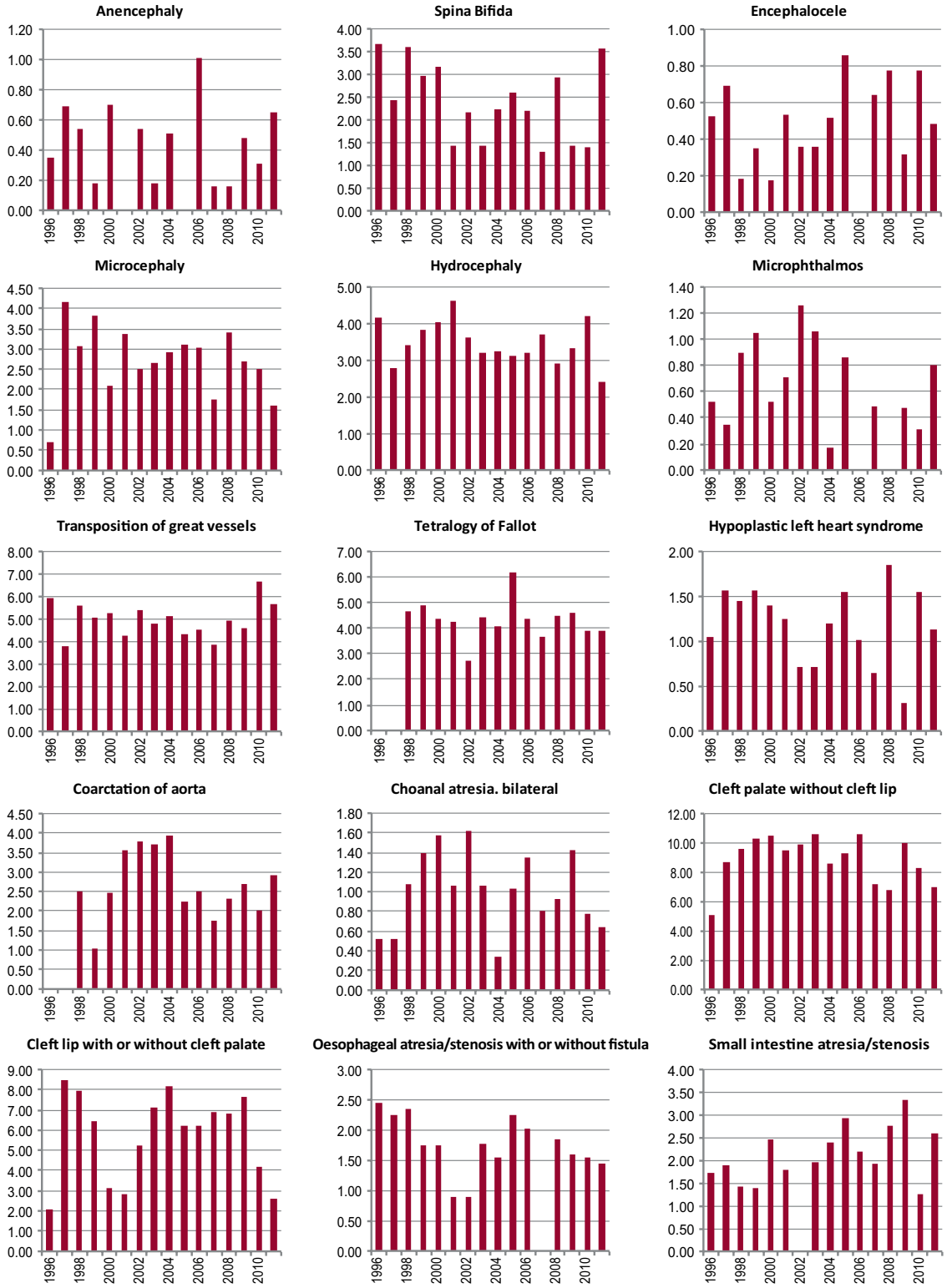
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births								
Anencephaly	6.36	4.12	1.71	0.55	0.42	0.45	0.35	
Spina bifida	11.67	9.38	5.13	3.84	2.71	2.12	2.12	
Encephalocele	nr	0.68*	0.73*	0.26*	0.39	0.42	0.60	
Microcephaly	nr	nr	nr	0.70*	3.31	2.84	2.40	
Holoprosencephaly	nr	nr	nr	nr	nr	nr	nr	
Hydrocephaly	5.63	3.60	2.72	3.32	3.74	3.26	3.32	
Anophthalmos	nr	nr	nr	0.00*	0.00	0.09*	0.13	
Microphthalmos	nr	nr	nr	0.52*	0.71	0.83*	0.41	
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	0.00*	0.00	0.10	0.00*	
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	0.81*	
Transposition of great vessels	nr	nr	0.55*	5.92*	4.79	4.82	5.15	
Tetralogy of Fallot	nr	nr	nr	nr	4.56*	4.37	4.11	
Hypoplastic left heart syndrome	nr	nr	0.82*	1.47*	1.45	1.04	1.11	
Coarctation of aorta	nr	nr	nr	nr	2.39*	3.23	2.34	
Choanal atresia, bilateral	nr	nr	nr	0.52*	1.13	1.08	0.92	
Cleft palate without cleft lip	5.73	6.89	6.35	5.27	9.70	9.78	7.84	
Cleft lip with or without cleft palate	9.17	9.11	6.87	2.67	5.78	6.59	5.63	
Oesophageal atresia/stenosis with or without fistula	1.25	2.14	1.60	2.64	1.80	1.70	1.61*	
Small intestine atresia/stenosis	nr	nr	nr	1.74*	1.80	2.36*	2.37	
Anorectal atresia/stenosis	1.98	2.61	2.09	3.08	2.33	2.43	1.96	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	69.03	71.47	46.19	
Hypospadias	10.94	14.41	12.11	11.83*	26.34	29.00	22.77	
Epispadias	nr	nr	nr	nr	nr	nr	nr	
Indeterminate sex	nr	nr	nr	nr	0.53	0.76	0.79	
Renal agenesis	nr	0.13*	0.64*	nr	3.35	3.09	2.69	
Cystic kidney	nr	nr	nr	5.05*	6.24	5.20	5.09	
Bladder exstrophy	nr	nr	nr	0.17*	0.48*	0.14	0.16	
Polydactyly, preaxial	nr	nr	nr	4.87*	8.52*	10.20	14.58	
Total Limb reduction defects (include unspecified)	3.44	3.80	3.10	1.75	2.61	2.88	2.51*	
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	2.01*	nr	
Diaphragmatic hernia	nr	1.52*	1.46*	nr	2.57*	2.32*	2.49*	
Omphalocele	2.61	2.18	1.26	3.28*	nr	nr	4.85*	
Gastroschisis	0.00	0.36	0.73*	nr	nr	nr	1.11*	
Unspecified Omphalocele/Gastroschisis	0.00	0.24	0.18*	nr	nr	5.01*	0.95*	
Prune belly sequence	nr	nr	nr	nr	nr	nr	nr	
Trisomy 13	nr	nr	nr	0.35*	0.42	0.59	0.35	
Trisomy 18	nr	nr	nr	0.70*	1.09	1.28	1.01	
Down syndrome, all ages (include age unknown)	8.76	9.23	9.14	9.33*	11.88	10.96	9.07	
<20	2.55	7.43	4.32*	nr	nr	nr	nr	
20-24	6.32	3.86	1.40*	nr	nr	nr	nr	
25-29	8.75	8.61	7.92*	nr	nr	nr	nr	
30-34	8.75	9.78	9.29*	nr	nr	nr	nr	
35-39	34.79	31.66	34.31*	nr	nr	nr	nr	
40-44	65.62	102.54	452.49*	nr	nr	nr	nr	
45+	0.00	215.83	0.00*	nr	nr	nr	nr	
unknown	---	---	---	---	---	---	---	

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

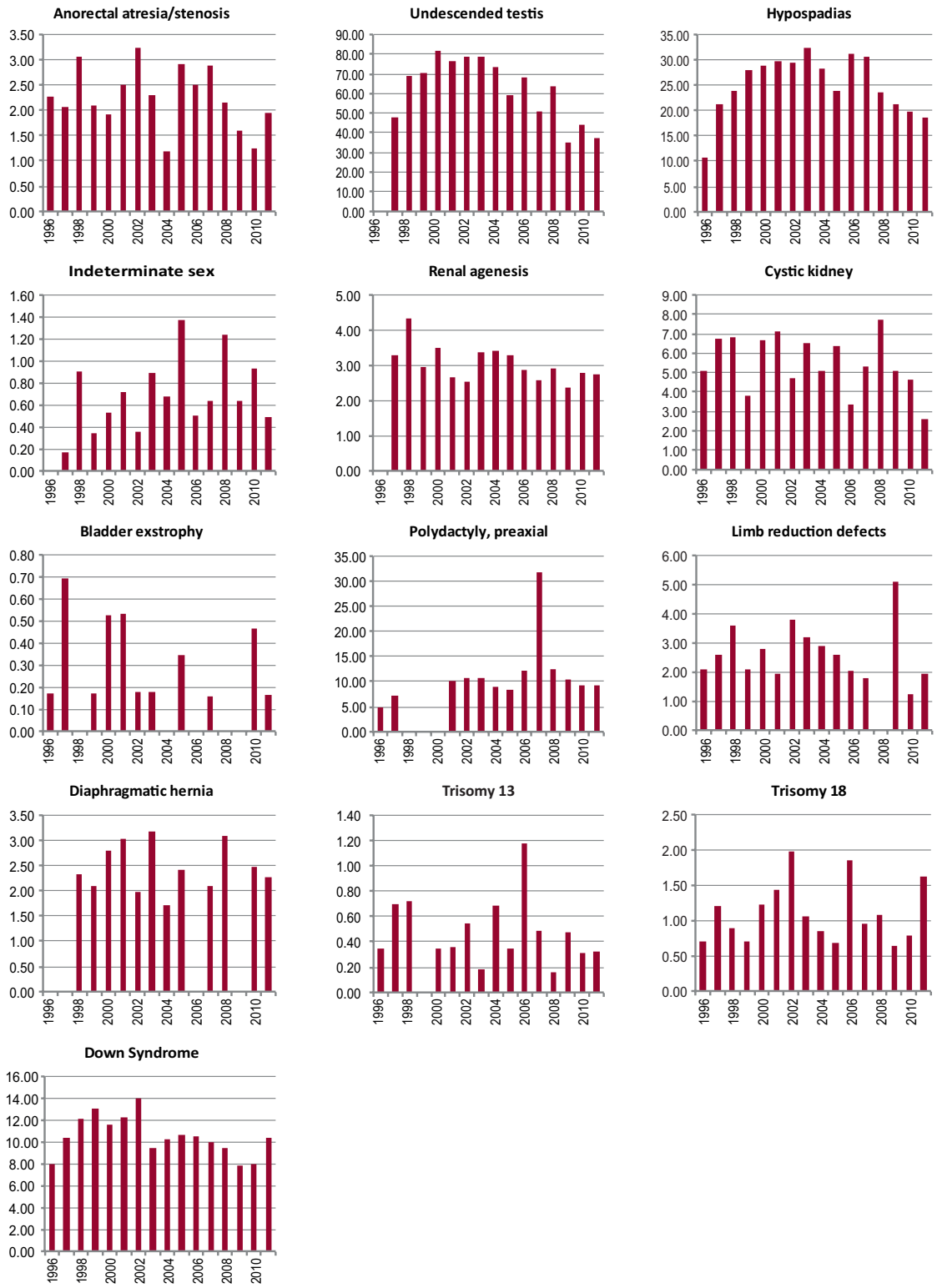
New Zealand

Time trends 1996-2011 (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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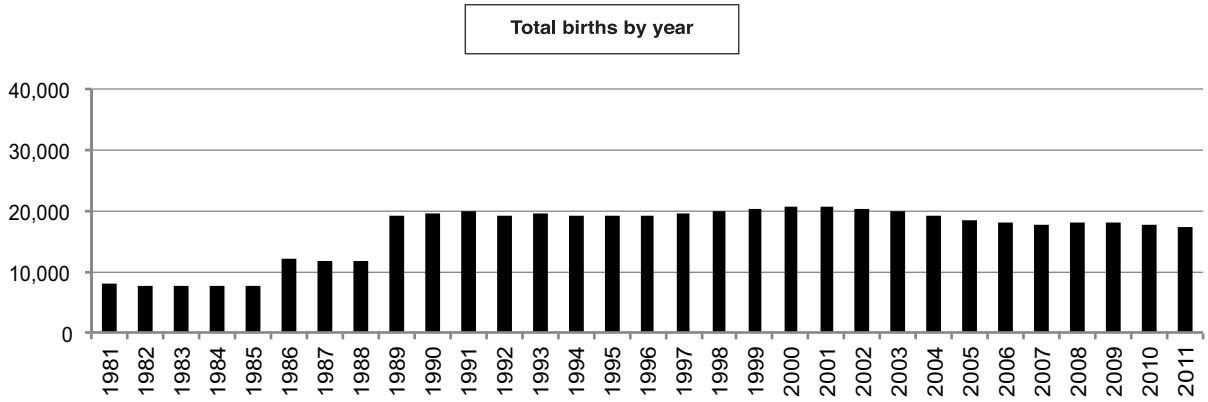
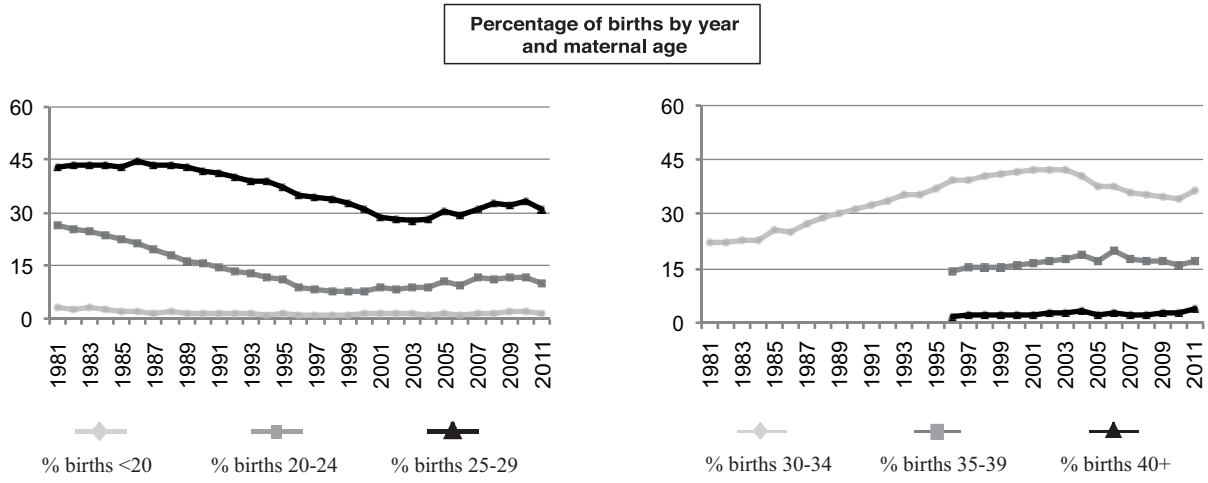
Website: www.eurocatnederland.nl

Northern Netherlands





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	22	88.0	Cystic kidney	15	35.7
Spina bifida	14	56.0	Limb reduction defects	10	29.4
Encephalocele	4	80.0	Diaphragmatic hernia	2	12.5
Holoprosencephaly	4	66.7	Omphalocele	7	41.2
Hydrocephaly	11	45.8	Gastroschisis	5	41.7
Hypoplastic left heart syndrome	13	65.0	Trisomy 13	9	64.3
Cleft palate without cleft lip	2	6.7	Trisomy 18	32	78.0
Cleft lip with or without cleft palate	8	11.8	Down syndrome	49	45.8
Renal agenesis	10	32.3			

Total ToPs with births defects = 251 (Ratio ToPs/Births: 4.74 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Northern Netherlands, 2011

Live births (LB)	17,124
Stillbirths (SB)	64
Total births	17,188
Number of terminations of pregnancy (ToP) for birth defects	74

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	8	5.24
Spina bifida	4	0	4	4.65
Encephalocele	0	0	0	0.00
Microcephaly	5	0	1	3.49
Holoprosencephaly	1	0	2	1.75
Hydrocephaly	3	0	1	2.33
Anophthalmos	0	0	1	0.58
Microphthalmos	3	0	0	1.75
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	2	0	0	1.16
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	7	0	1	4.65
Tetralogy of Fallot	5	0	1	3.49
Hypoplastic left heart syndrome	1	0	2	1.75
Coarctation of aorta	2	1	0	1.75
Choanal atresia, bilateral	1	0	0	0.58
Cleft palate without cleft lip	3	0	0	1.75
Cleft lip with or without cleft palate	20	2	3	14.55
Oesophageal atresia/stenosis with or without fistula	0	0	1	0.58
Small intestine atresia/stenosis	2	0	1	1.75
Anorectal atresia/stenosis	8	1	3	6.98
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	41	0	1	24.44
Epispadias	1	0	0	0.58
Indeterminate sex	1	0	0	0.58
Renal agenesis	4	1	2	4.07
Cystic kidney	9	0	3	6.98
Bladder exstrophy	2	0	0	1.16
Polydactyly, preaxial	5	0	0	2.91
Total Limb reduction defects (include unspecified)	4	0	3	4.07
Transverse	4	0	2	3.49
Preaxial	0	0	0	0.00
Postaxial	1	0	0	0.58
Intercalary	0	0	1	0.58
Mixed	1	0	0	0.58
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	5	1	1	4.07
Omphalocele	1	1	3	2.91
Gastroschisis	3	1	1	2.91
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	1	2	2.33
Trisomy 18	1	2	4	4.07
Down syndrome, all ages (include age unknown)	16	0	17	19.20
<20	0	0	0	0.00
20-24	0	0	0	6.31
25-29	5	0	1	15.92
30-34	2	0	3	23.18
35-39	5	0	6	54.30
40-44	3	0	6	261.50
45+	1	0	1	222.22
unknown	nr	nr	nr	---

nr = data not reported or not available

Northern Netherlands, Previous years rates 1981 - 2011

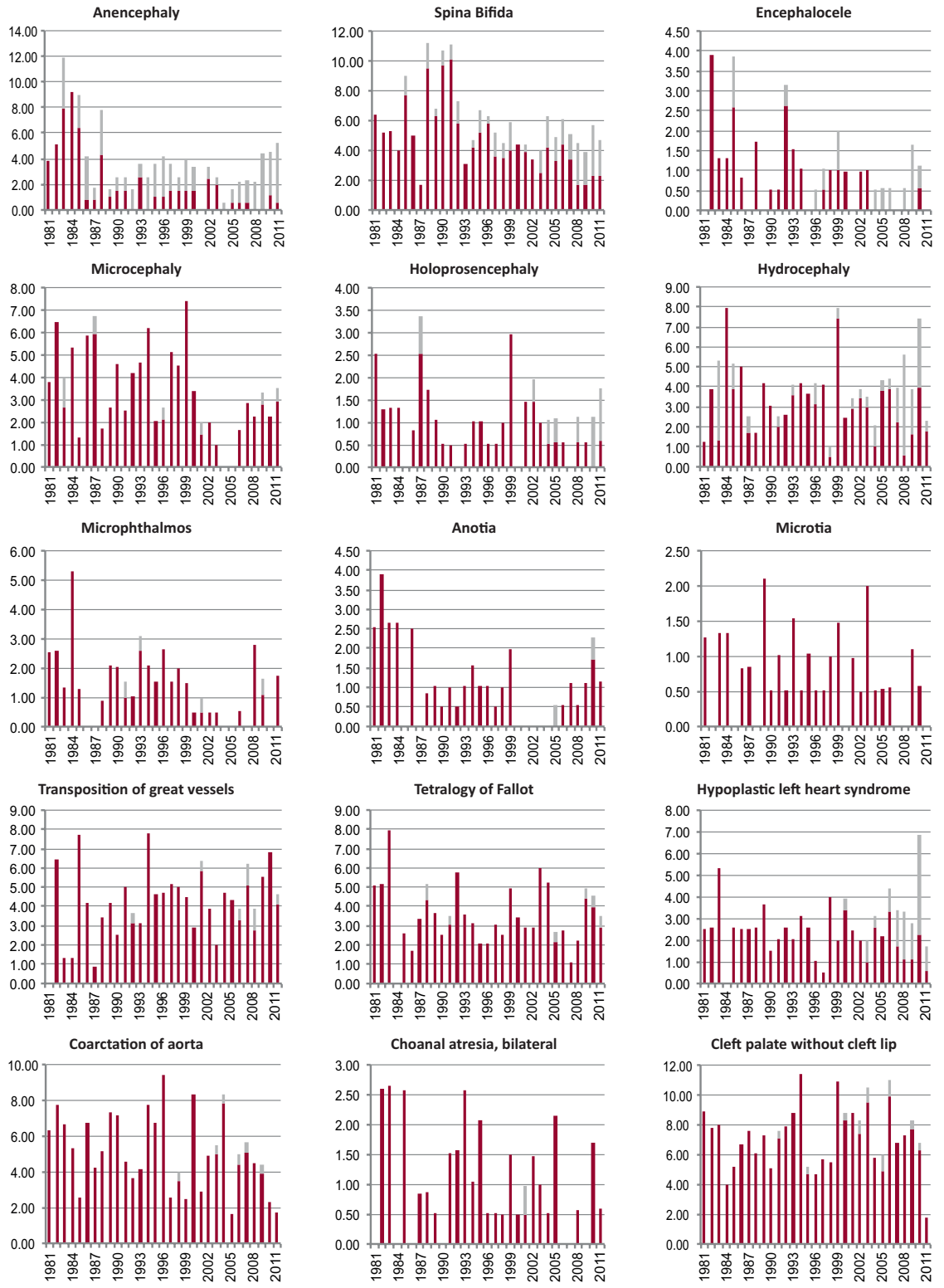
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**7,877**	**42,560**	**82,023**	**96,178**	**100,583**	**96,266**	**88,511**
Anencephaly		3.81	7.52	2.93	3.12	2.68	2.08	3.73
Spina bifida		6.35	5.64	8.66	5.61	4.87	4.88	4.75
Encephalocele		0.00	2.11	0.49	1.25	0.99	0.73	0.68
Microcephaly		3.81	4.70	3.54	3.95	4.47	0.93	2.82
Holoprosencephaly		2.54	0.94	1.22	0.62	1.19	1.14	0.90
Hydrocephaly		1.27	5.40	2.93	3.74	3.78	3.64	4.63
Anophthalmos		0.00	0.23	0.37	0.31	0.00	0.00	0.23
Microphthalmos		2.54	1.88	1.46	2.08	1.29	0.31	1.24
Unspecified Anophthalmos/Microphthalmos		nr	nr	nr	nr	0.98*	1.39	nr
Anotia		2.54	2.35	0.73	1.04	0.70	0.21	1.24
Microtia		1.27	0.70	0.98	0.83	0.80	0.83	0.34
Unspecified Anotia/Microtia		nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels		0.00	4.23	3.41	4.78	4.77	3.74	5.42
Tetralogy of Fallot		5.08	3.29	3.54	3.33	3.38	3.95	3.28
Hypoplastic left heart syndrome		2.54	2.58	2.44	2.29	2.58	2.70	3.62
Coarctation of aorta		6.35	5.87	5.85	6.34	4.08	5.09	3.73
Choanal atresia, bilateral		0.00	1.41	0.73	1.56	0.80	1.04	0.56
Cleft palate without cleft lip		8.89	6.34	6.71	7.59	7.95	8.31	6.21
Cleft lip with or without cleft palate		15.23	17.39	14.14	15.80	14.12	14.23	12.99
Oesophageal atresia/stenosis with or without fistula		1.27	2.82	2.68	3.12	3.88	3.95	1.47
Small intestine atresia/stenosis		3.81	2.58	2.56	3.02	2.19	1.45	2.03
Anorectal atresia/stenosis		1.27	2.82	3.66	2.91	3.88	3.53	5.20
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr	nr
Hypospadias		19.04	13.63	9.88	10.71	16.70	21.19	21.58
Epispadias		0.00	0.23	0.73	0.52	0.60	0.42	0.79
Indeterminate sex		0.00	0.23	0.24	0.10	0.50	0.52	0.79
Renal agenesis		3.81	3.99	4.27	4.78	4.87	4.57	5.54
Cystic kidney		2.54	2.11	6.34	4.68	3.48	5.82	6.89
Bladder exstrophy		0.00	0.23	0.24	0.10	0.20	0.42	0.68
Polydactyly, preaxial		0.00	2.82	1.58	2.08	2.49	0.62	1.58
Total Limb reduction defects (include unspecified)		8.89	7.28	5.49	7.17	5.57	6.65	6.10
Transverse		5.08	4.46	2.68	4.05	3.38	4.57	4.41
Preaxial		1.27	1.41	0.61	1.04	0.60	1.14	0.90
Postaxial		2.54	0.47	1.22	1.66	0.80	0.00	1.81
Intercalary		1.27	0.00	0.00	0.31	0.20	0.21	0.23
Mixed		1.27	0.23	0.24	0.42	0.30	0.52	1.81
Unspecified		nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia		2.54	2.35	2.68	2.60	2.98	2.70	2.49
Omphalocele		2.54	1.41	2.93	3.22	1.89	1.97	2.60
Gastroschisis		1.27	1.17	0.49	0.42	1.19	0.93	1.81
Unspecified Omphalocele/Gastroschisis		nr	nr	nr	nr	nr	nr	nr
Prune belly sequence		0.00	0.23	0.49	0.42	0.50	0.10	0.11
Trisomy 13		0.00	0.94	1.22	1.35	0.89	1.25	2.60
Trisomy 18		3.81	1.88	2.56	2.08	3.38	5.82	7.34
Down syndrome, all ages (include age unknown)		10.16	13.16	14.14	14.66	15.31	16.72	18.53
<20	0.00	0.00	0.00	0.00	0.00	0.00	0.00	
20-24		9.58	8.12	8.15	8.14	2.47	6.79	5.00
25-29		5.90	8.05	11.19	4.65	10.23	9.37	7.75
30-34		11.42	14.88	11.18	15.20	9.47	10.65	15.64
35-39		49.38	44.20	38.51	36.14	37.60	33.09	41.44
40-44		nr	nr	nr	160.77*	91.00	120.63	83.72
45+	nr	nr	nr	0.00*	149.25	121.95	857.14	
unknown		---	---	---	---	---	---	---

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

Northern Netherlands

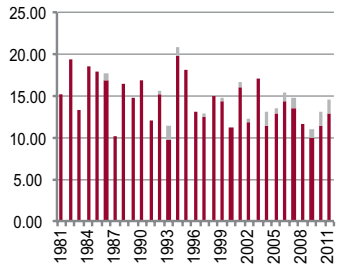
Time trends 1981-2011 (Birth prevalence rates per 10,000)



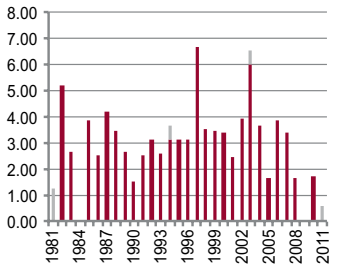
Note: L+S rates, ToP rates

Northern Netherlands

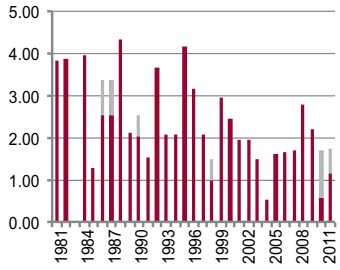
Cleft lip with or without cleft palate



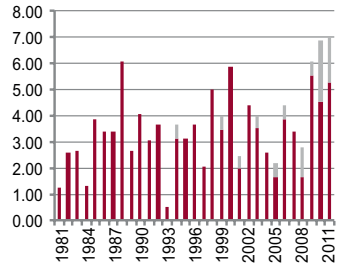
Oesophageal atresia/stenosis with or without fistula



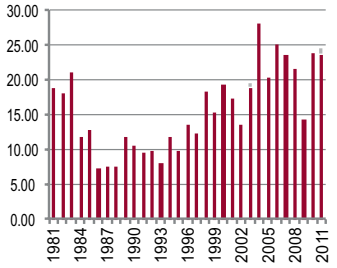
Small intestine atresia/stenosis



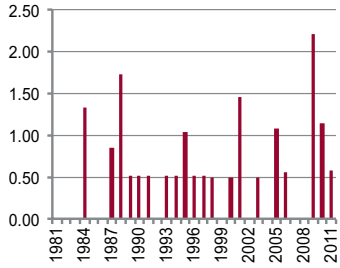
Anorectal atresia/stenosis



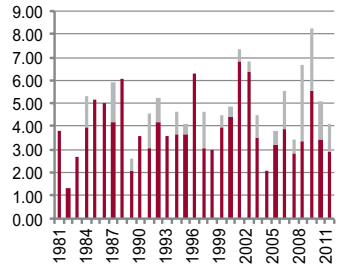
Hypospadias



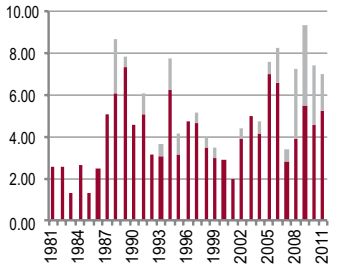
Epispadias



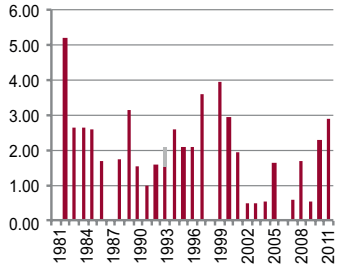
Renal agenesis



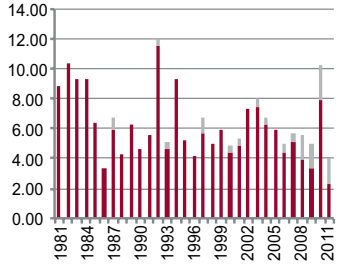
Cystic kidney



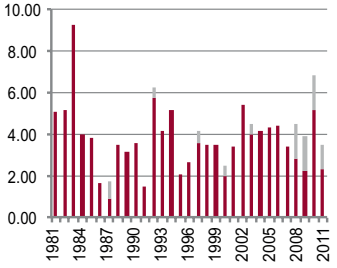
Polydactyly, preaxial



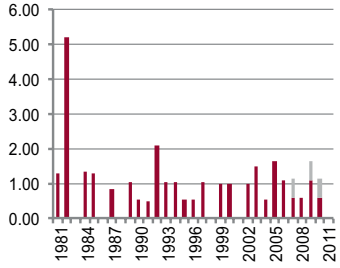
Limb reduction defects



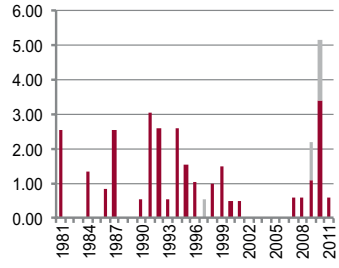
Limb reduction defects - transverse



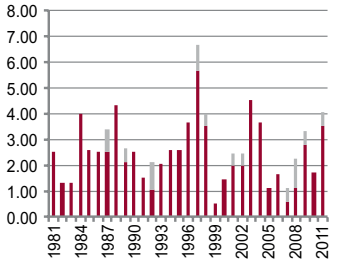
Limb reduction defects - preaxial



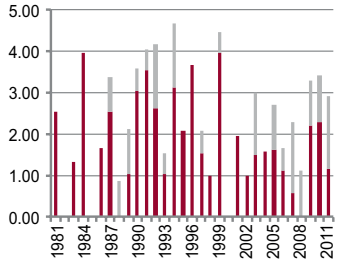
Limb reduction defects - postaxial



Diaphragmatic hernia

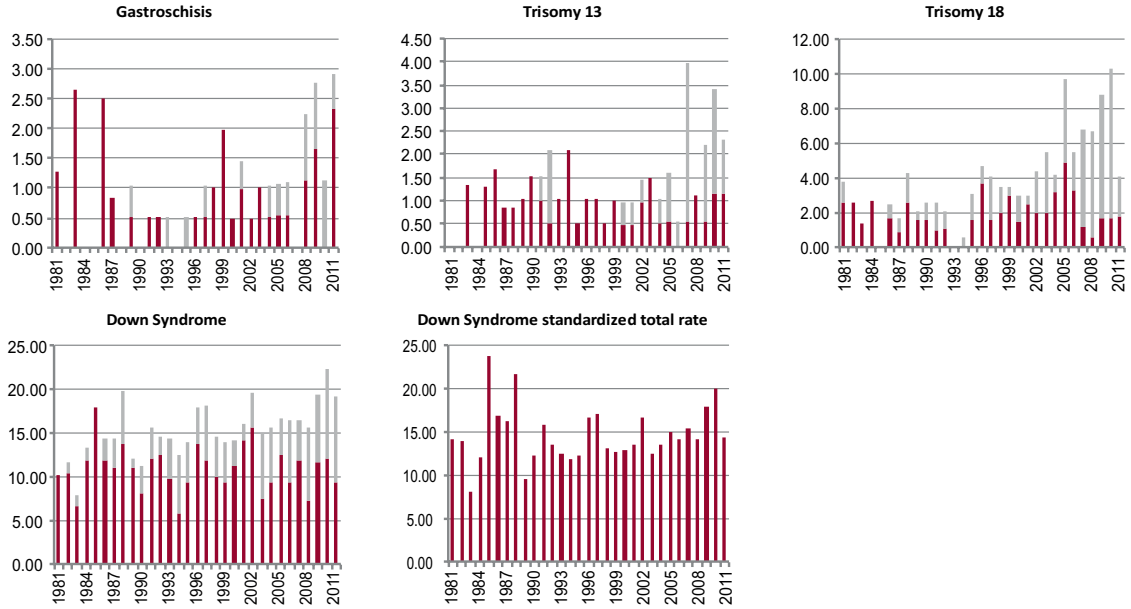


Omphalocele



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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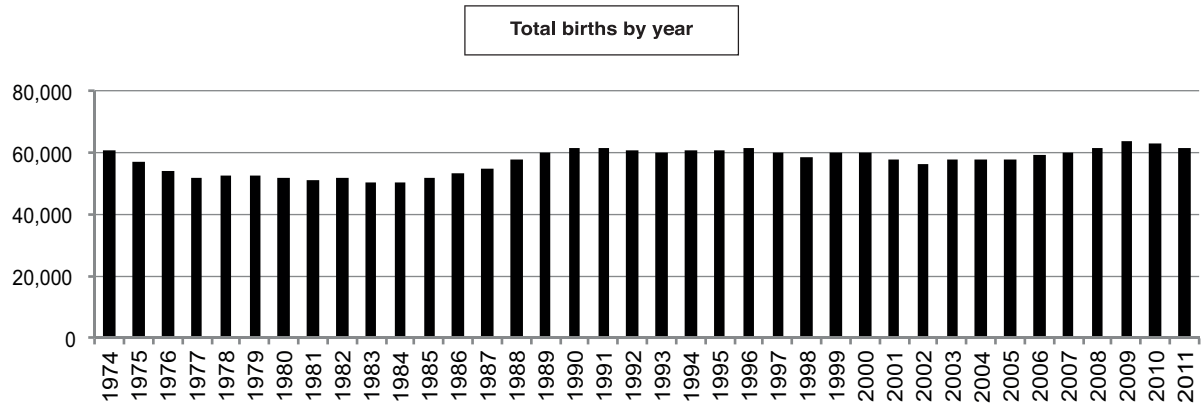
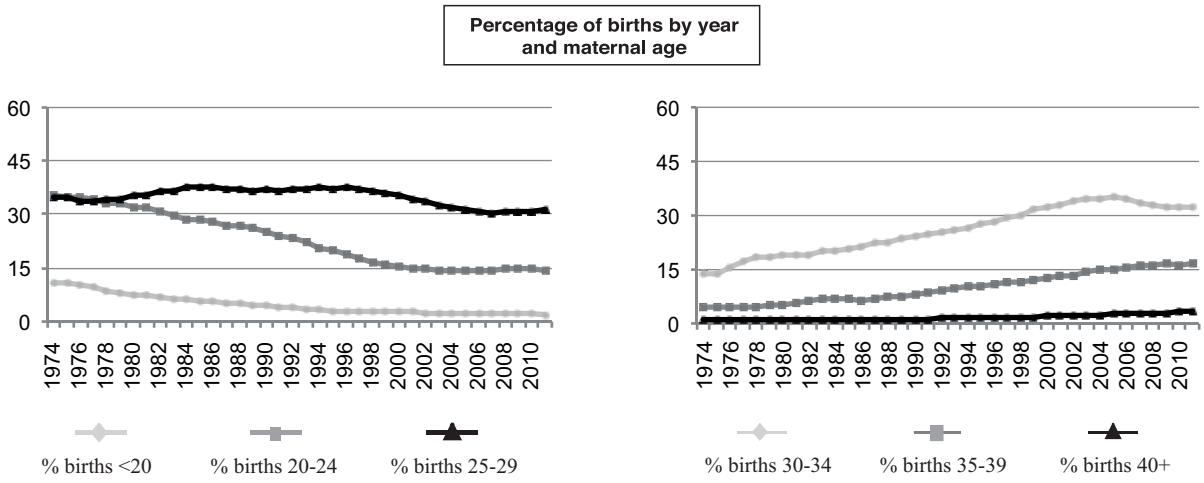
Norway: MBRN





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	54	91.5	Cystic kidney	47	49.5
Spina bifida	61	64.9	Limb reduction defects	33	34.0
Encephalocele	16	94.1	Diaphragmatic hernia	12	20.0
Holoprosencephaly	19	79.2	Omphalocele	32	56.1
Hydrocephaly	48	42.9	Gastroschisis	2	3.2
Hypoplastic left heart syndrome	27	45.0	Trisomy 13	28	77.8
Cleft palate without cleft lip	8	5.7	Trisomy 18	60	71.4
Cleft lip with or without cleft palate	26	11.9	Down syndrome	131	34.7
Renal agenesis	21	75.0			

Total ToPs with births defects = 797 (Ratio ToPs/Births: 4.25 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Norway: MBRN, 2011

Live births (LB)	61,116
Stillbirths (SB)	256
Total births	61,637
Number of terminations of pregnancy (ToP) for birth defects	265

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	16	2.76
Spina bifida	9	0	25	5.52
Encephalocele	0	0	3	0.49
Microcephaly	0	1	1	0.32
Holoprosencephaly	0	1	6	1.14
Hydrocephaly	16	0	17	5.35
Anophthalmos	0	1	0	0.16
Microphthalmos	1	0	0	0.16
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	3	0	0	0.49
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	19	0	5	3.89
Tetralogy of Fallot	19	0	4	3.73
Hypoplastic left heart syndrome	12	1	6	3.08
Coarctation of aorta	15	0	3	2.92
Choanal atresia, bilateral	4	1	0	0.81
Cleft palate without cleft lip	40	1	3	7.14
Cleft lip with or without cleft palate	60	2	9	11.52
Oesophageal atresia/stenosis with or without fistula	22	1	1	3.89
Small intestine atresia/stenosis	12	0	0	1.95
Anorectal atresia/stenosis	20	2	4	4.22
Undescended testis (36 weeks of gestation or later)	127	0	0	20.60
Hypospadias	83	2	0	13.79
Epispadias	1	0	0	0.16
Indeterminate sex	4	0	0	0.65
Renal agenesis	2	0	5	1.14
Cystic kidney	16	0	11	4.38
Bladder exstrophy	2	0	1	0.49
Polydactyly, preaxial	45	0	7	8.44
Total Limb reduction defects (include unspecified)	21	1	10	5.19
Transverse	6	1	7	2.27
Preaxial	5	0	5	1.62
Postaxial	0	0	1	0.16
Intercalary	1	0	1	0.32
Mixed	10	0	4	2.27
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	15	0	4	3.08
Omphalocele	8	0	10	2.92
Gastroschisis	22	0	0	3.57
Unspecified Omphalocele/Gastroschisis	33	1	13	7.63
Prune belly sequence	8	1	9	2.92
Trisomy 13	0	1	11	1.95
Trisomy 18	7	2	23	5.19
Down syndrome, all ages (include age unknown)	86	5	48	22.55
<20	1	0	0	8.56
20-24	4	0	2	6.71
25-29	15	0	5	10.39
30-34	16	3	8	13.53
35-39	36	1	22	57.92
40-44	13	1	11	123.64
45+	1	0	0	100.00
unknown	0	0	0	---

nr = data not reported or not available

Norway: MBRN, Previous years rates 1974 - 2011

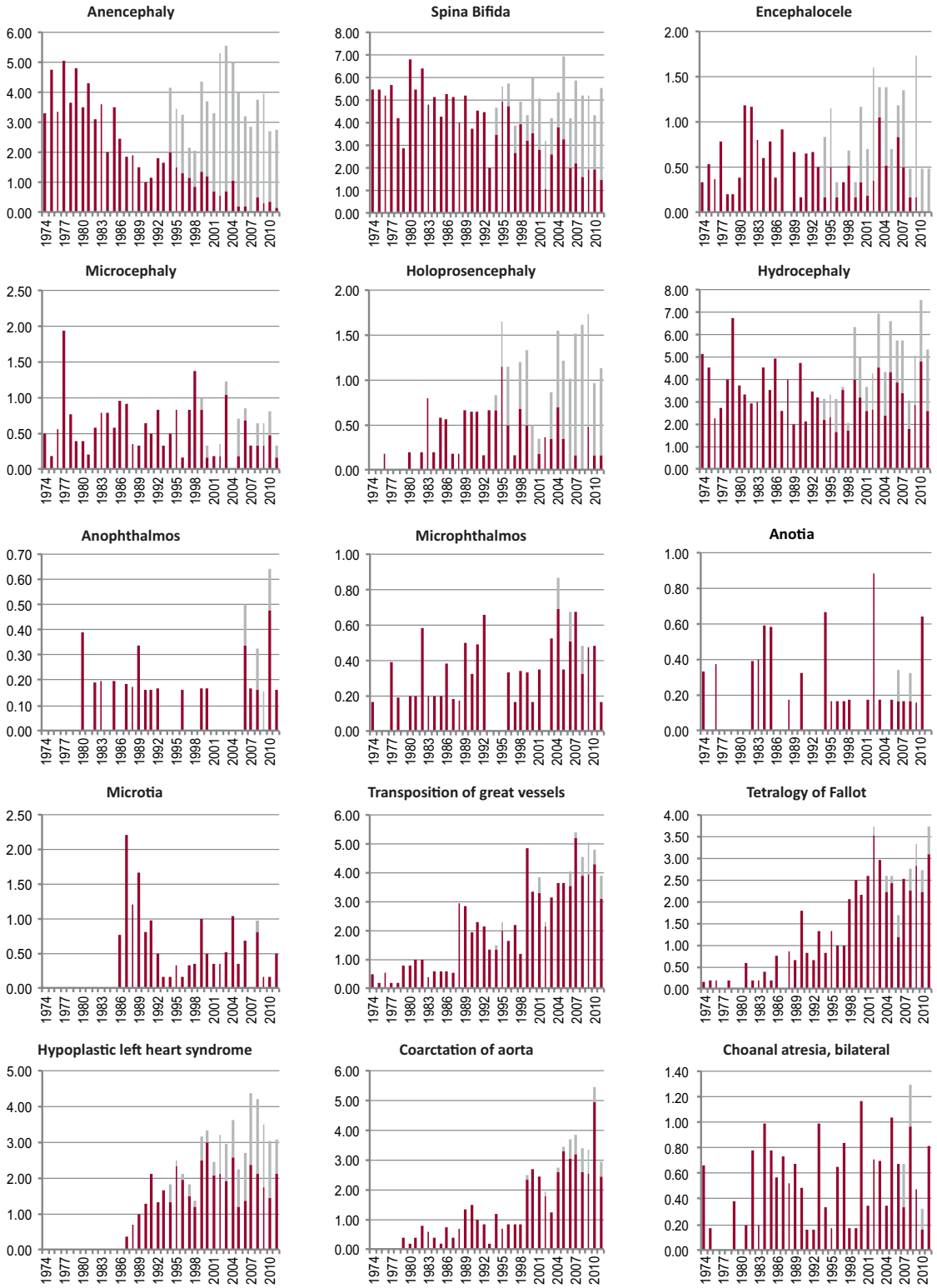
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**171,536**	**258,504**	**256,935**	**295,191**	**303,101**	**295,874**	**289,216**	**308,911**
Anencephaly	3.79	4.26	2.92	1.46	2.87	3.11	4.60	3.20
Spina bifida	5.36	4.99	5.18	4.51	4.49	4.83	4.77	5.21
Encephalocele	0.41	0.54	0.74	0.47	0.69	0.64	1.24	0.91
Microcephaly	0.41	0.73	0.74	0.54	0.53	0.74	0.62	0.55
Holoprosencephaly	0.06	0.04	0.47	0.47	0.89	0.71	1.00	1.39
Hydrocephaly	4.02	4.10	3.78	3.08	3.23	4.16	5.57	5.34
Anophthalmos	0.00	0.08	0.12	0.20	0.07	0.07	0.10	0.29
Microphthalmos	0.06	0.19	0.31	0.34	0.20	0.27	0.48	0.45
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.23	0.00	0.39	0.10	0.20	0.10	0.31	0.26
Microtia	nr	nr	0.76*	1.36	0.26	0.51	0.59	0.36
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.41	0.58	0.62	2.13	1.78	3.08	3.35	4.73
Tetralogy of Fallot	0.17	0.15	0.35	0.85	1.02	2.06	2.70	3.01
Hypoplastic left heart syndrome	nr	nr	nr	1.12	1.88	2.43	2.94	3.63
Coarctation of aorta	nr	0.32*	0.54	0.98	0.73	1.86	2.63	3.79
Choanal atresia, bilateral	0.29	0.12	0.66	0.51	0.46	0.54	0.69	0.71
Cleft palate without cleft lip	4.55	4.76	5.57	5.22	5.15	6.35	7.30	6.77
Cleft lip with or without cleft palate	14.69	14.35	13.89	13.18	13.82	13.05	13.28	12.14
Oesophageal atresia/stenosis with or without fistula	2.39	1.66	1.79	2.64	1.81	2.40	2.56	3.40
Small intestine atresia/stenosis	0.70	1.04	1.05	1.32	1.68	1.08	1.04	1.13
Anorectal atresia/stenosis	1.69	1.66	2.22	2.47	1.88	2.43	3.11	4.43
Undescended testis (36 weeks of gestation or later)	17.14	17.25	14.32	17.48	16.13	20.62	28.80	21.79
Hypospadias	10.90	14.24	14.40	17.11	14.42	15.01	16.11	13.50
Epispadias	0.23	0.23	0.54	0.30	0.16	0.37	0.14	0.23
Indeterminate sex	1.40	3.48	4.05	4.20	7.65	3.35	0.35	0.71
Renal agenesis	0.12	0.27	0.97	1.52	1.39	1.62	0.93	1.72
Cystic kidney	0.52	0.58	1.32	1.80	2.31	4.12	5.39	5.05
Bladder exstrophy	0.35	0.23	0.43	0.27	0.33	0.30	0.24	0.45
Polydactyly, preaxial	nr	nr	nr	nr	nr	8.12*	9.47	8.38
Total Limb reduction defects (include unspecified)	7.35	9.05	7.04	6.74	6.73	5.27	4.32	4.89
Transverse	nr	nr	nr	3.23*	3.83	2.23	2.42	2.01
Preaxial	nr	nr	nr	0.93*	0.40	0.51	0.48	1.10
Postaxial	nr	nr	nr	0.87*	0.40	0.24	0.10	0.26
Intercalary	nr	nr	nr	0.16*	0.49	0.30	0.10	0.16
Mixed	nr	nr	nr	0.44*	0.73	1.49	1.56	2.20
Unspecified	nr	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	1.22	2.67	2.26	2.57	2.38	2.87	2.45	3.08
Omphalocele	2.39	2.24	1.95	1.96	2.24	2.10	2.35	2.98
Gastroschisis	1.34	1.24	1.56	1.96	2.51	2.74	2.77	3.50
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	0.85*	0.38	2.20
Prune belly sequence	nr	nr	nr	nr	nr	1.41*	1.38	2.82
Trisomy 13	nr	nr	nr	nr	nr	1.47*	1.56	2.27
Trisomy 18	nr	nr	nr	nr	nr	2.99*	4.22	4.73
Down syndrome, all ages (include age unknown)	9.68	10.14	10.90	10.60	10.43	14.33	18.46	18.39
<20	1.66	3.31	4.43	3.59	3.01	3.82	6.29	7.14
20-24	6.47	6.46	7.79	6.17	4.22	2.71	6.81	7.07
25-29	7.11	8.35	6.92	5.50	7.24	6.86	7.55	8.28
30-34	12.20	10.18	14.44	13.72	11.37	10.74	14.34	11.72
35-39	36.49	36.90	34.27	33.39	22.77	42.29	45.67	46.72
40-44	123.60	134.42	63.69	74.78	85.14	142.57	136.80	142.18
45+	263.16	90.91	99.01	327.87	326.80	344.83	149.81	209.79
unknown	---	---	---	---	---	---	---	---

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

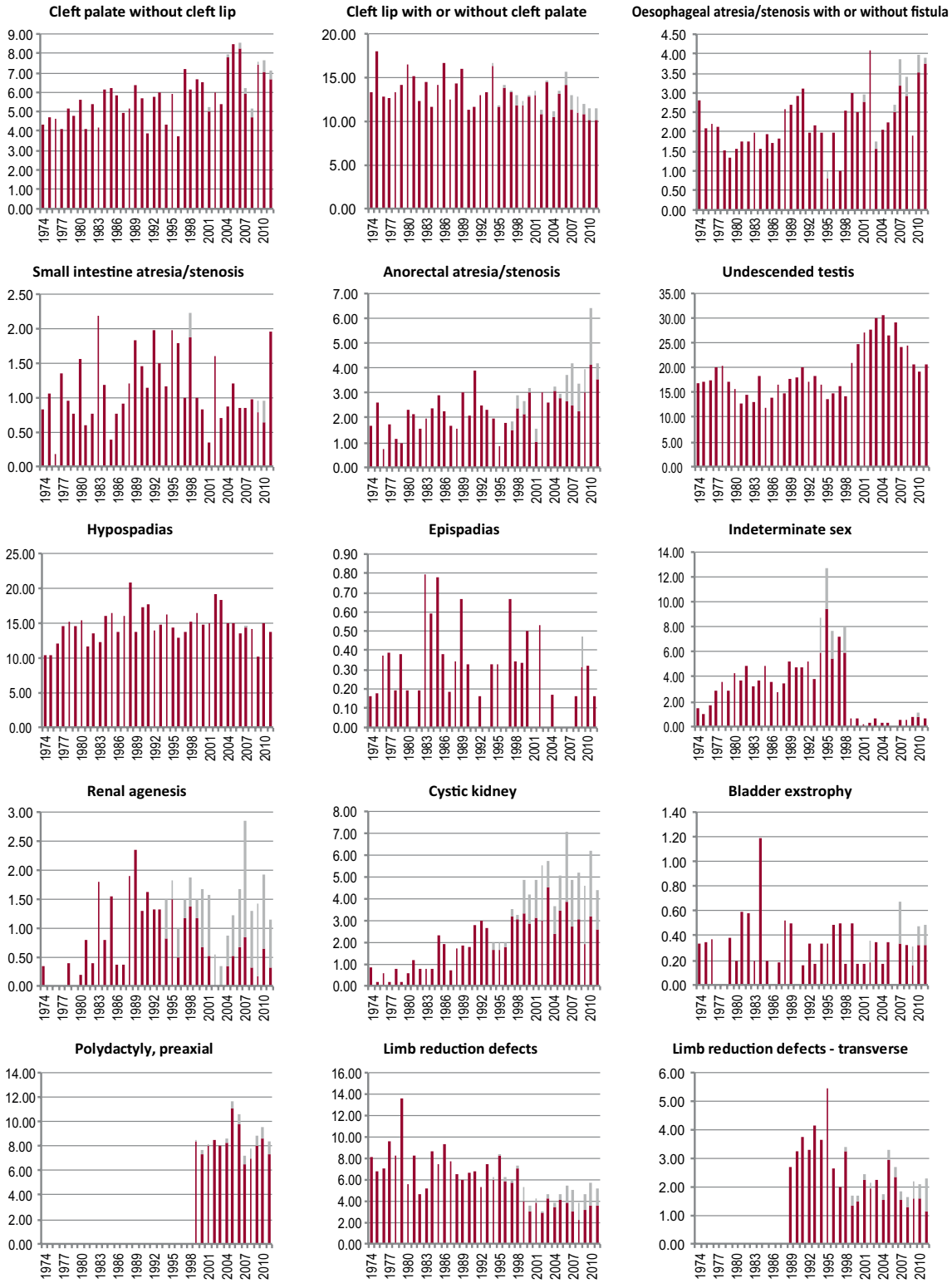
Norway: MBRN

Time trends 1974-2011 (Birth prevalence rates per 10,000)



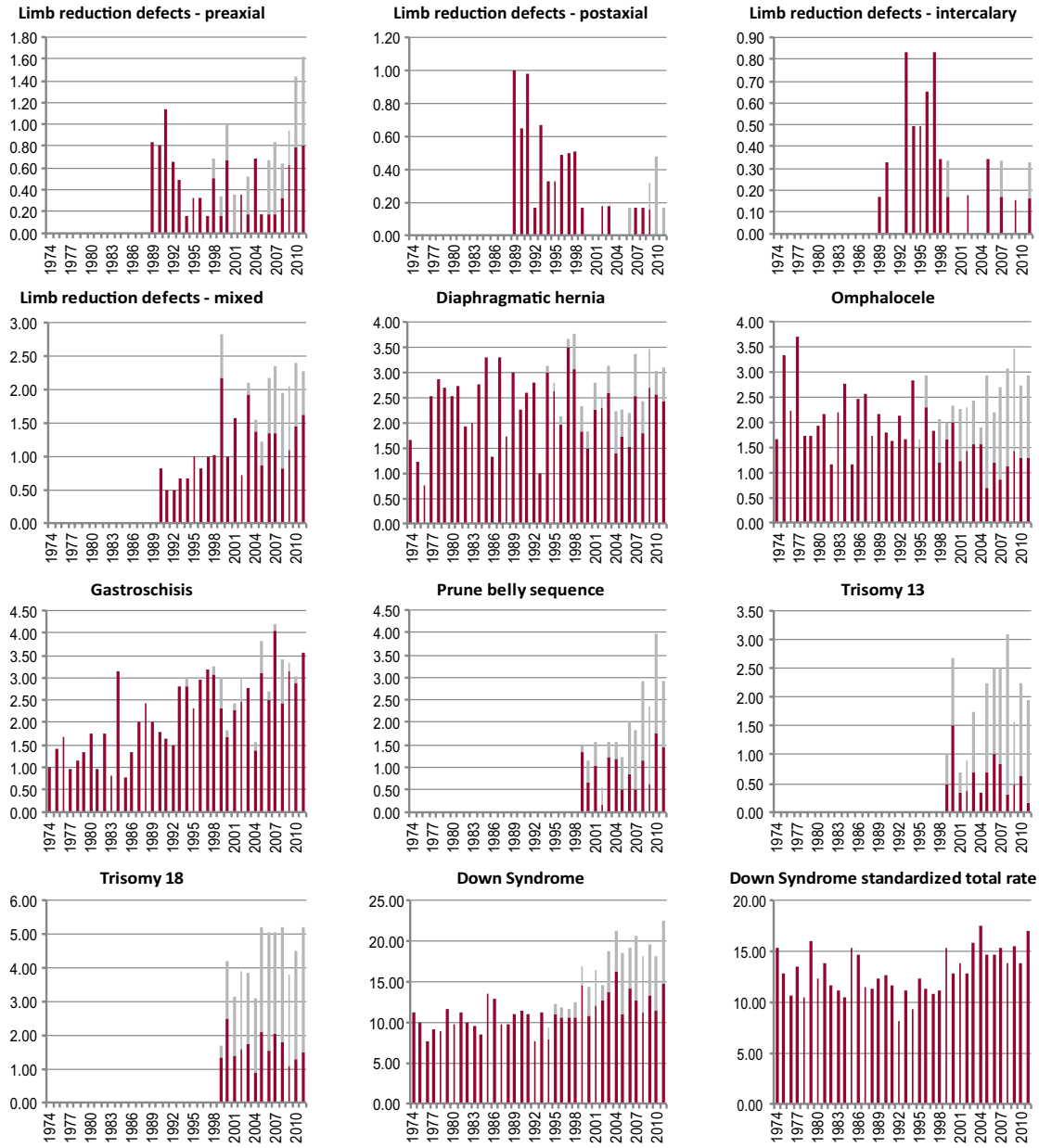
Note: L+S rates, ToP rates

Norway: MBRN



Note: L+S rates, ToP rates

Norway: MBRN



Note: L+S rates, ToP rates

Saudi Arabia: MSD-BDR

Medical Service Department- Birth Defect Registry

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Saudi Arabia: MSD-BDR, 2011

Live births (LB)	9,440
Stillbirths (SB)	100
Total births	9,540
Number of terminations of pregnancy (ToP) for birth defects	7

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	2	6	10.48
Spina bifida	7	1	0	8.39
Encephalocele	4	0	0	4.19
Microcephaly	10	2	0	12.58
Holoprosencephaly	1	0	0	1.05
Hydrocephaly	11	1	0	12.58
Anophthalmos	0	0	0	0.00
Microphthalmos	7	0	0	7.34
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	4	0	0	4.19
Tetralogy of Fallot	5	0	0	5.24
Hypoplastic left heart syndrome	6	0	0	6.29
Coarctation of aorta	5	0	0	5.24
Choanal atresia, bilateral	1	0	0	1.05
Cleft palate without cleft lip	4	0	0	4.19
Cleft lip with or without cleft palate	13	0	0	13.63
Oesophageal atresia/stenosis with or without fistula	5	0	0	5.24
Small intestine atresia/stenosis	4	0	0	4.19
Anorectal atresia/stenosis	9	0	0	9.43
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	45	0	0	47.17
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	1.05
Renal agenesis	4	1	0	5.24
Cystic kidney	22	1	0	24.11
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	9	0	0	9.43
Total Limb reduction defects (include unspecified)	5	1	0	6.29
Transverse	2	0	0	2.10
Preaxial	0	1	0	1.05
Postaxial	1	0	0	1.05
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	2	0	0	2.10
Diaphragmatic hernia	5	0	0	5.24
Omphalocele	1	0	0	1.05
Gastroschisis	0	0	0	0.00
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	0	1.05
Trisomy 18	2	0	0	2.10
Down syndrome, all ages (include age unknown)	20	0	0	20.96
<20	0	0	0	0.00
20-24	0	0	0	0.00
25-29	3	0	0	10.52
30-34	3	0	0	12.53
35-39	7	0	0	48.78
40-44	7	0	0	139.44
45+	0	0	0	0.00
unknown	0	0	0	---

nr = data not reported or not available

Slovak Republic

Teratologic Information Centre, Slovak Medical University in Bratislava

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 only 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 only according to the running research projects.

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

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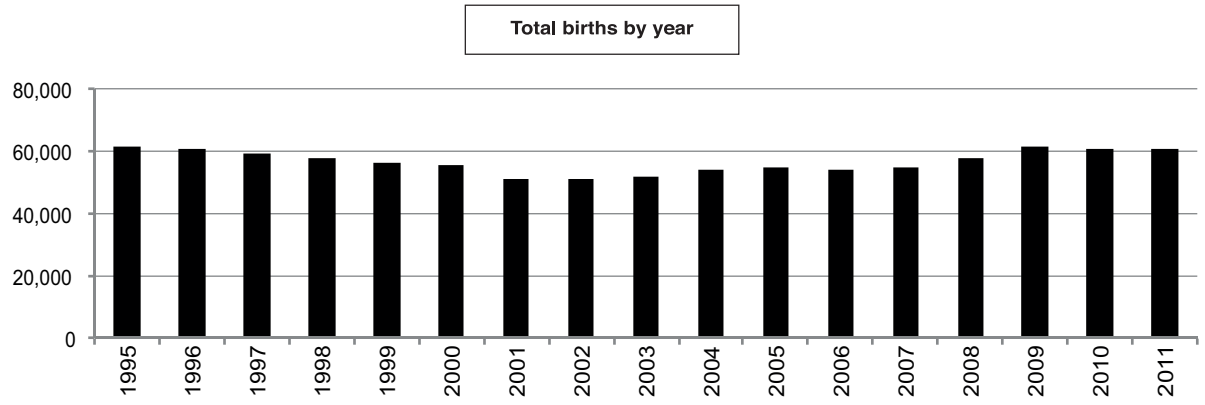
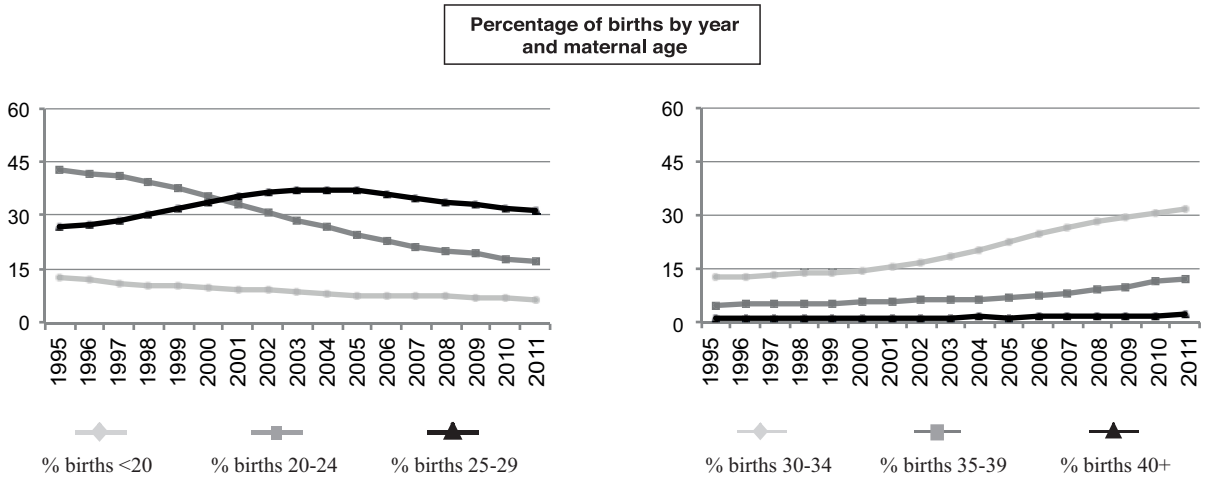
Slovak Republic





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	16	72.7	Cystic kidney	1	4.8
Spina bifida	7	16.3	Limb reduction defects	0	0.0
Encephalocele	7	53.8	Diaphragmatic hernia	1	3.0
Holoprosencephaly	2	22.2	Omphalocele	3	27.3
Hydrocephaly	11	22.0	Gastroschisis	1	5.3
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	1	25.0
Cleft palate without cleft lip	4	4.5	Trisomy 18	8	44.4
Cleft lip with or without cleft palate	1	0.6	Down syndrome	35	22.4
Renal agenesis	2	1.7			

Total ToPs with births defects = 169 (Ratio ToPs/Births: 0.92 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Slovak Republic, 2011

Live births (LB)	60,813
Stillbirths (SB)	190
Total births	61,003
Number of terminations of pregnancy (ToP) for birth defects	53

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP(*)	Total rate
Anencephaly	1	0	6	1.15
Spina bifida	14	0	4	2.95
Encephalocele	1	0	2	0.49
Microcephaly	7	0	0	1.15
Holoprosencephaly	3	0	1	0.66
Hydrocephaly	11	0	3	2.29
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.16
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.16
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	9	0	0	1.48
Tetralogy of Fallot	8	0	0	1.31
Hypoplastic left heart syndrome	17	0	0	2.79
Coarctation of aorta	5	0	0	0.82
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	30	0	2	5.25
Cleft lip with or without cleft palate	43	0	0	7.05
Oesophageal atresia/stenosis with or without fistula	8	0	0	1.31
Small intestine atresia/stenosis	6	0	0	0.98
Anorectal atresia/stenosis	13	0	0	2.13
Undescended testis (36 weeks of gestation or later)	96	0	0	15.74
Hypospadias	92	0	0	15.08
Epispadias	1	0	0	0.16
Indeterminate sex	1	0	0	0.16
Renal agenesis	38	0	0	6.23
Cystic kidney	10	0	0	1.64
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	20	0	0	3.28
Total Limb reduction defects (include unspecified)	16	0	0	2.62
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	7	0	0	1.15
Omphalocele	6	0	0	0.98
Gastroschisis	6	0	1	1.15
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	0	0.16
Trisomy 18	2	0	2	0.66
Down syndrome, all ages (include age unknown)	44	0	8	8.52
<20	2	0	0	5.41
20-24	4	0	1	4.87
25-29	10	0	0	5.24
30-34	11	0	4	7.83
35-39	14	0	2	21.49
40-44	2	0	1	26.88
45+	1	0	0	136.99
unknown	0	0	0	---

nr = data not reported or not available
(*) Birth Defects under-reported in ToP

Slovak Republic, Previous years rates 1995 - 2011

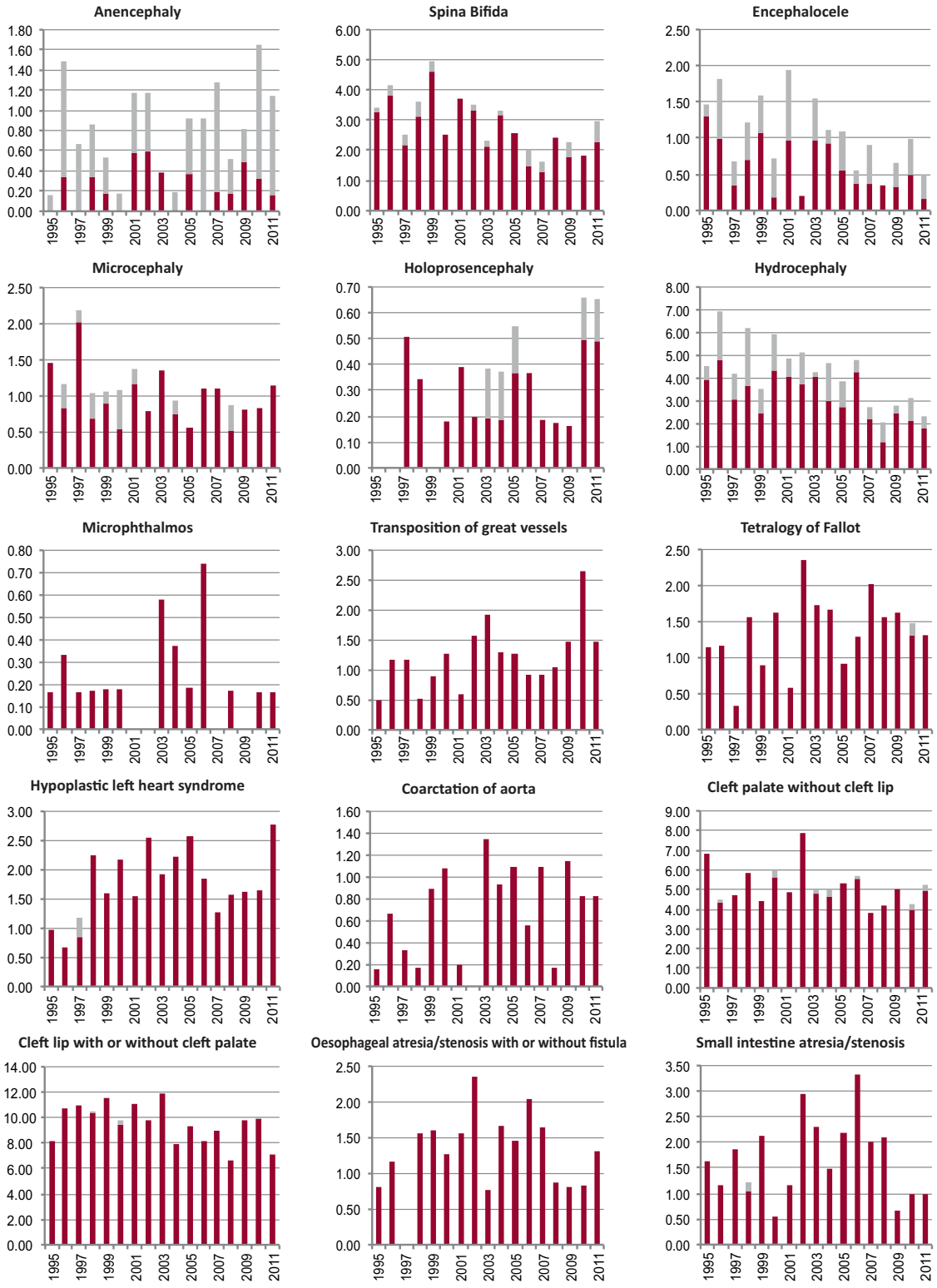
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996*	1997-2001	2002-2006	2007-2011
Total births					**122,031**	**280,410**	**265,670**	**295,264**
Anencephaly					0.82	0.68	0.72	1.08
Spina bifida					3.77	3.46	2.75	2.24
Encephalocele					1.64	1.21	0.90	0.68
Microcephaly					1.31	1.36	0.94	0.95
Holoprosencephaly					0.00	0.29	0.38	0.37
Hydrocephaly					5.74	4.96	4.52	2.61
Anophthalmos					0.00	0.07	0.08	0.00
Microphthalmos					0.25	0.14	0.38	0.10
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00	0.00
Anotia					0.08	0.18	0.04	0.20
Microtia					0.41	0.32	0.23	0.10
Unspecified Anotia/Microtia					0.16	0.21	0.68	0.72*
Transposition of great vessels					0.82	0.89	1.39	1.52
Tetralogy of Fallot					1.15	1.00	1.58	1.59
Hypoplastic left heart syndrome					0.82	1.75	2.22	1.80
Coarctation of aorta					0.41	0.53	0.79	0.81
Choanal atresia, bilateral					0.16	0.25	0.11	0.17
Cleft palate without cleft lip					5.65	5.17	5.76	4.54
Cleft lip with or without cleft palate					9.42	10.77	9.41	8.50
Oesophageal atresia/stenosis with or without fistula					0.98	1.18	1.66	1.08
Small intestine atresia/stenosis					1.39	1.39	2.45	1.32
Anorectal atresia/stenosis					0.82	2.57	2.71	2.61
Undescended testis (36 weeks of gestation or later)					5.16	7.70	8.13	12.60
Hypospadias					23.52	23.07	22.51	16.02
Epispadias					0.08	0.21	0.19	0.20
Indeterminate sex					0.41	0.57	0.19	0.24
Renal agenesis					1.48	4.03	5.95	5.93
Cystic kidney					0.57	1.11	1.77	1.02
Bladder exstrophy					0.00	0.25	0.11	0.07
Polydactyly, preaxial					1.56	2.21	3.27	2.84
Total Limb reduction defects (include unspecified)					4.43	3.03	4.10	2.71
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					0.08	0.00	0.04	0.00*
Diaphragmatic hernia					0.98	1.39	1.69	1.69
Omphalocele					0.33	0.68	0.68	0.58
Gastroschisis					0.57	1.00	1.17	0.91
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00	0.11*
Prune belly sequence					0.00	0.04	0.23	0.03
Trisomy 13					0.16	0.32	0.38	0.20
Trisomy 18					0.08	0.32	0.64	0.78
Down syndrome, all ages (include age unknown)					9.18	9.59	10.01	8.64
<20					8.18	5.67	2.81	3.77*
20-24					7.57	5.14	3.96	3.60*
25-29					6.02	6.58	6.93	4.42*
30-34					12.87	12.43	10.80	9.35*
35-39					27.30	40.77	37.53	23.15*
40-44					43.29	90.36	109.02	61.46*
45+					0.00	241.94	283.69	188.68*
unknown					---	---	---	---

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

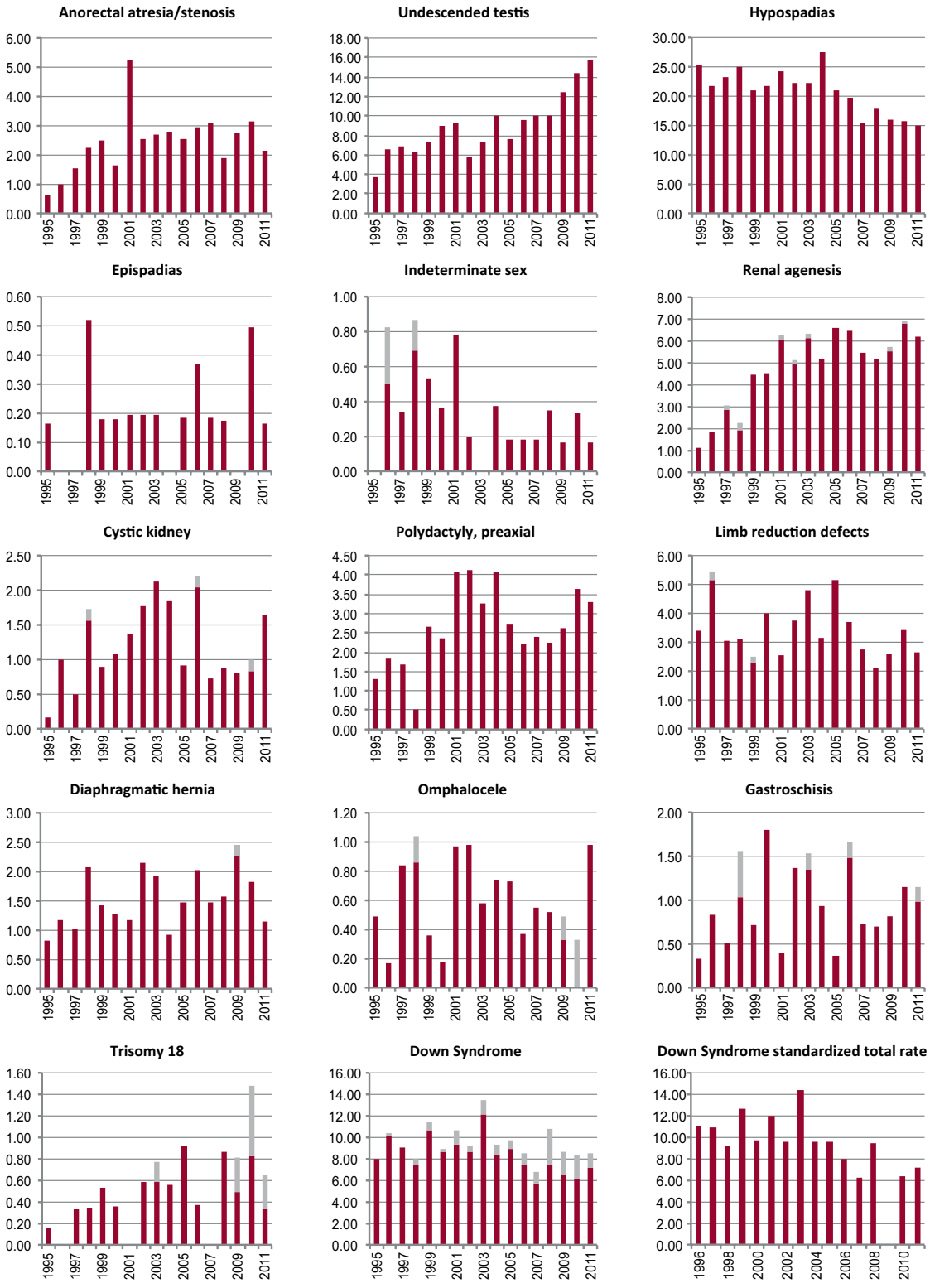
Slovak Republic

Time trends 1995-2011 (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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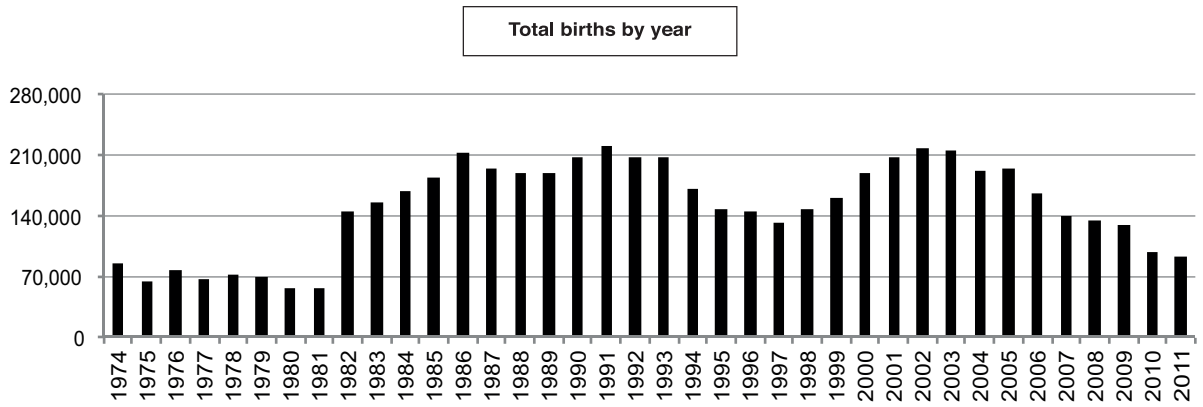
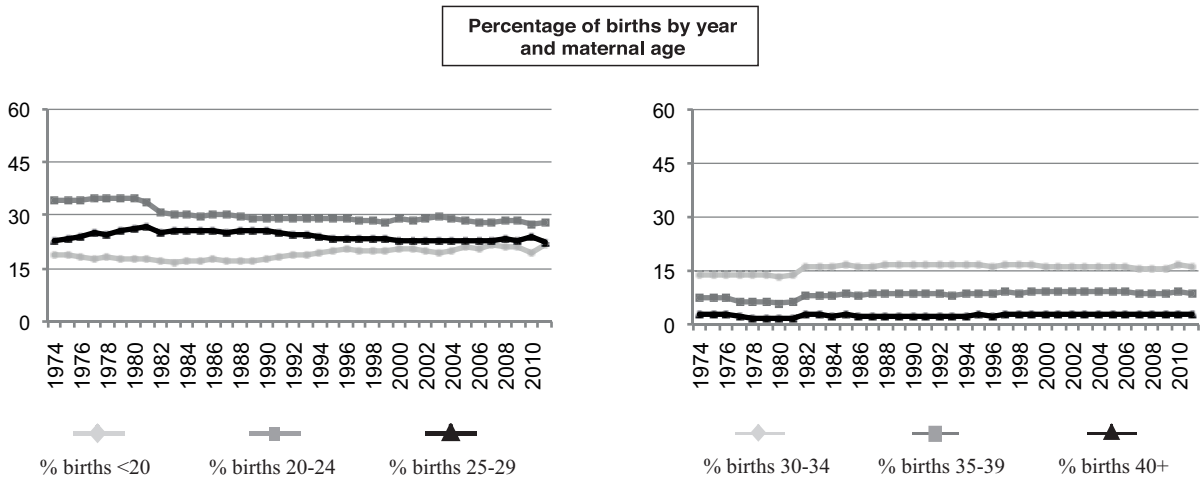
South America: ECLAMC





South America: ECLAMC, 2011

Live births (LB)	91,678
Stillbirths (SB)	1,125
Total births	92,803
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	38	26		6.90
Spina bifida	66	6		7.76
Encephalocele	41	3		4.74
Microcephaly	48	4		5.60
Holoprosencephaly	7	1		0.86
Hydrocephaly	191	7		21.34
Anophthalmos	3	3		0.65
Microphthalmos	20	3		2.48
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	1	2		0.32
Microtia	47	1		5.17
Unspecified Anotia/Microtia	8	0		0.86
Transposition of great vessels	4	0		0.43
Tetralogy of Fallot	13	2		1.62
Hypoplastic left heart syndrome	3	0		0.32
Coarctation of aorta	3	1		0.43
Choanal atresia, bilateral	5	1		0.65
Cleft palate without cleft lip	54	4		6.25
Cleft lip with or without cleft palate	102	11		12.18
Oesophageal atresia/stenosis with or without fistula	41	3		4.74
Small intestine atresia/stenosis	41	3		4.74
Anorectal atresia/stenosis	57	10		7.22
Undescended testis (36 weeks of gestation or later)	92	2		10.13
Hypospadias	87	2		9.59
Epispadias	0	0		0.00
Indeterminate sex	24	4		3.02
Renal agenesis	31	5		3.88
Cystic kidney	58	3		6.57
Bladder exstrophy	1	0		0.11
Polydactyly, preaxial	29	1		3.23
Total Limb reduction defects (include unspecified)	63	6		7.44
Transverse	10	0		1.08
Preaxial	7	3		1.08
Postaxial	2	0		0.22
Intercalary	6	0		0.65
Mixed	3	0		0.32
Unspecified	35	3		4.09
Diaphragmatic hernia	50	6		6.03
Omphalocele	38	9		5.06
Gastroschisis	94	3		10.45
Unspecified Omphalocele/Gastroschisis	14	2		1.72
Prune belly sequence	3	1		0.43
Trisomy 13	6	2		0.86
Trisomy 18	15	1		1.72
Down syndrome, all ages (include age unknown)	176	2		19.18
<20	16	0		8.24
20-24	26	0		10.30
25-29	16	0		7.93
30-34	26	1		18.62
35-39	46	1		59.93
40-44	40	0		178.81
45+	6	0		291.26
unknown	0	0		---

South America: ECLAMC, Previous years rates 1974 - 2011

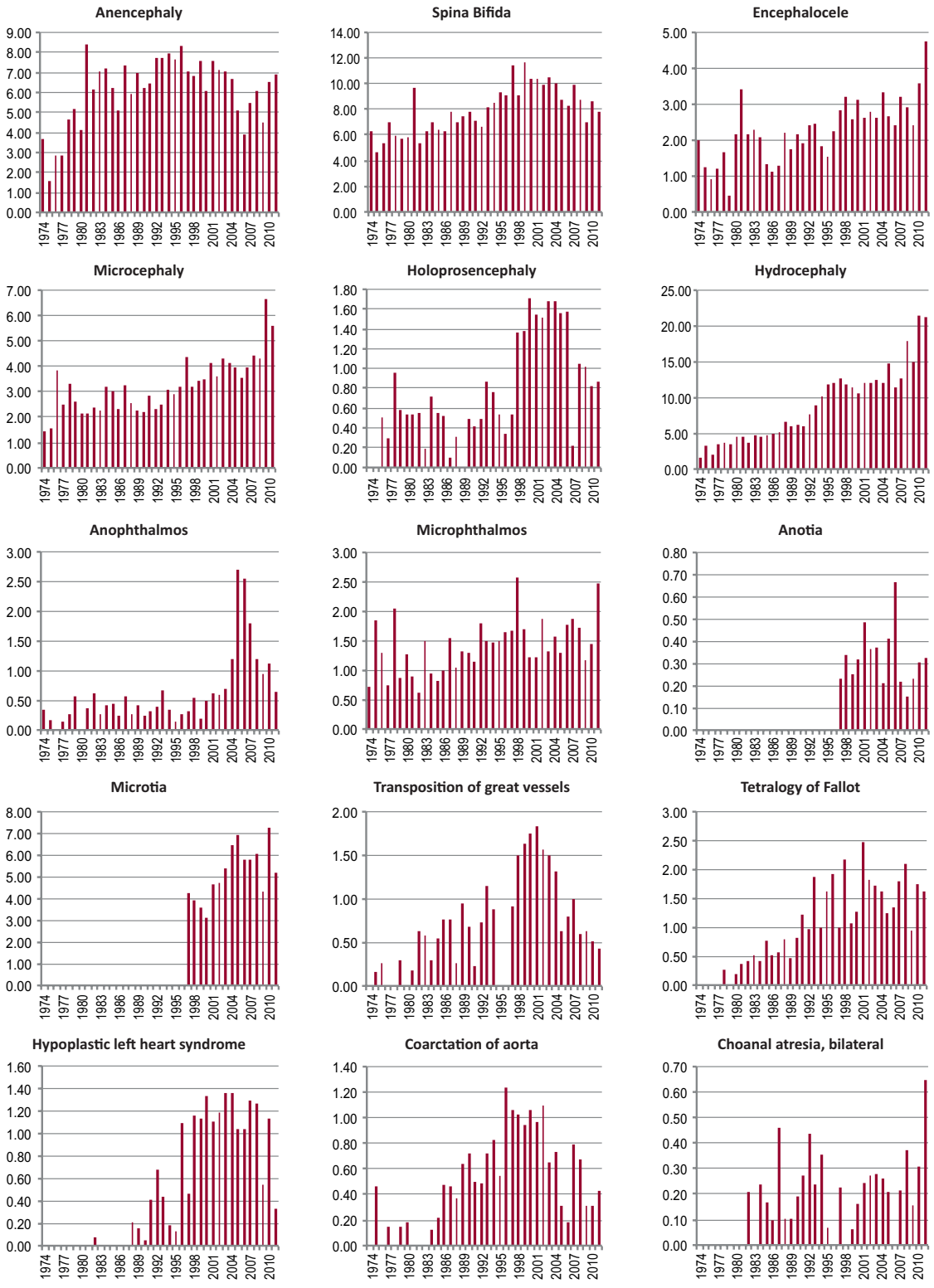
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**228,167**	**321,052**	**861,574**	**1,001,967**	**878,906**	**832,415**	**981,311**	**592,191**
Anencephaly	2.76	4.95	6.28	6.58	7.84	7.03	6.08	5.79
Spina bifida	5.48	6.73	6.29	7.44	8.25	10.56	9.54	8.46
Encephalocele	1.40	1.68	1.73	1.87	2.14	2.86	2.77	3.28
Microcephaly	2.28	2.59	2.63	2.61	2.75	3.72	3.91	4.83
Holoprosencephaly	0.18	0.59	0.51	0.27	0.61	1.36	1.60	0.78
Hydrocephaly	2.24	3.89	4.53	6.01	9.88	11.66	12.52	17.21
Anophthalmos	0.18	0.28	0.38	0.36	0.39	0.44	1.48	1.18
Microphthalmos	1.23	1.18	0.97	1.27	1.58	1.62	1.56	1.71
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	nr	0.34	0.40	0.24
Microtia	nr	nr	nr	nr	nr	3.90	5.83	5.67
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	0.11	0.09	0.39
Transposition of great vessels	0.13	0.09	0.57	0.57	0.74	1.57	1.18	0.66
Tetralogy of Fallot	0.00	0.16	0.53	0.79	1.46	1.65	1.57	1.64
Hypoplastic left heart syndrome	0.00	0.00	0.01	0.17	0.50	1.07	1.20	0.95
Coarctation of aorta	0.13	0.09	0.19	0.54	0.74	1.01	0.62	0.52
Choanal atresia, bilateral	0.00	0.00	0.14	0.23	0.24	0.14	0.21	0.32
Cleft palate without cleft lip	2.76	3.33	3.49	3.41	3.81	4.50	4.91	4.46
Cleft lip with or without cleft palate	11.04	10.96	10.40	10.46	11.54	12.61	14.01	11.72
Oesophageal atresia/stenosis with or without fistula	1.84	2.15	2.39	2.90	2.90	3.53	3.64	4.10
Small intestine atresia/stenosis	0.13	1.12	1.56	1.52	1.90	2.61	3.12	2.94
Anorectal atresia/stenosis	2.32	3.36	3.69	3.97	4.78	5.18	5.60	5.62
Undescended testis (36 weeks of gestation or later)	1.36	2.09	4.02	4.61	4.95	5.99	7.63	9.79
Hypospadias	3.90	3.58	4.87	3.66	4.86	5.20	4.64	9.19
Epispadias	0.18	0.06	0.37	0.35	0.22	0.23	0.18	0.12
Indeterminate sex	0.92	1.40	2.25	1.66	1.92	2.05	2.39	2.85
Renal agenesis	0.44	0.44	0.71	1.11	1.92	2.39	2.56	2.97
Cystic kidney	0.57	0.59	1.17	1.80	2.47	4.37	3.78	5.29
Bladder exstrophy	0.04	0.19	0.26	0.29	0.32	0.35	0.29	0.20
Polydactyly, preaxial	2.89	2.49	2.44	2.64	2.74	3.21	4.22	3.14
Total Limb reduction defects (include unspecified)	3.64	4.80	5.26	4.90	5.72	6.48	7.44	7.60
Transverse	1.84	2.59	2.62	2.56	2.88	3.22	3.38	1.86
Preaxial	0.53	0.84	1.09	0.92	1.29	1.61	1.35	1.10
Postaxial	0.26	0.34	0.41	0.28	0.49	0.43	0.44	0.35
Intercalary	0.53	0.44	0.45	0.47	0.40	0.60	0.62	0.74
Mixed	0.39	0.44	0.59	0.54	0.51	0.50	1.46	1.49
Unspecified	0.09	0.16	0.09	0.13	0.16	0.11	0.19	2.06
Diaphragmatic hernia	0.75	0.93	1.35	1.99	2.58	3.74	3.72	3.88
Omphalocele	1.23	1.34	2.19	2.26	2.73	3.20	3.82	4.54
Gastroschisis	0.04	0.22	0.53	0.70	1.75	2.94	4.12	9.59
Unspecified Omphalocele/Gastroschisis	0.35	0.34	0.43	0.34	0.75	1.26	1.12	0.61
Prune belly sequence	0.00	0.03	0.70	0.72	0.96	1.14	0.87	0.62
Trisomy 13	0.18	0.19	0.55	0.42	0.66	0.94	0.76	0.57
Trisomy 18	0.22	0.25	0.93	0.93	1.23	2.05	1.83	1.32
Down syndrome, all ages (include age unknown)	13.63	15.48	14.53	15.80	16.35	18.84	19.02	17.70
<20	4.82	9.94	6.23	7.08	7.29	7.98	7.83	8.43
20-24	7.80	6.92	6.40	7.37	8.35	9.24	9.21	8.40
25-29	7.87	8.41	7.67	7.39	8.86	10.07	8.91	10.12
30-34	11.83	17.42	14.04	17.04	15.04	17.58	16.62	16.66
35-39	49.82	56.79	42.10	48.65	45.92	54.88	54.95	52.77
40-44	132.97	207.77	147.69	142.88	167.15	168.16	179.76	140.05
45+	240.30	405.06	240.47	312.15	266.38	371.45	358.82	263.79
unknown	---	---	---	---	---	---	---	---

nr = data not reported or not available

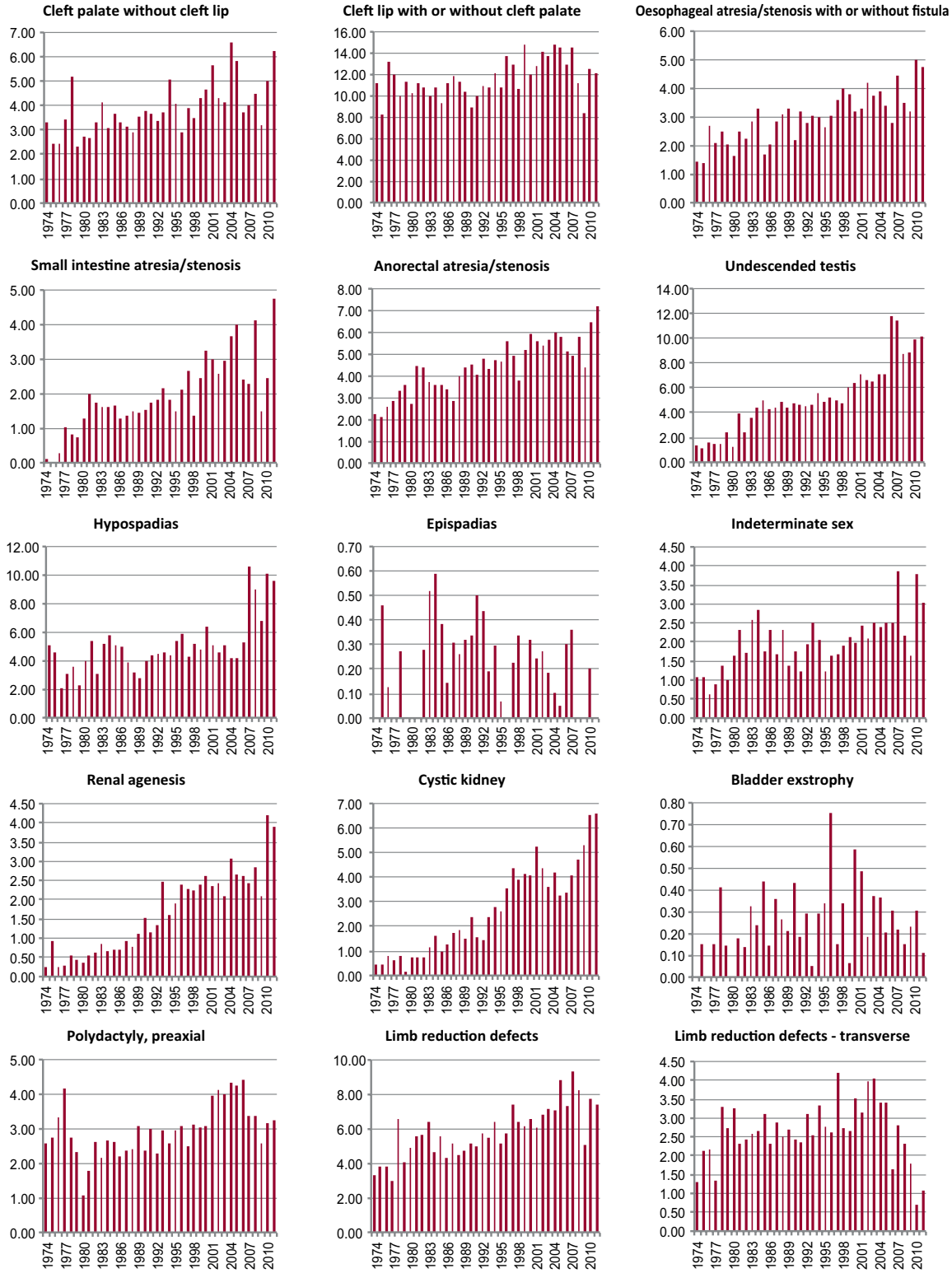
South America: ECLAMC

Time trends 1974-2011 (Birth prevalence rates per 10,000)



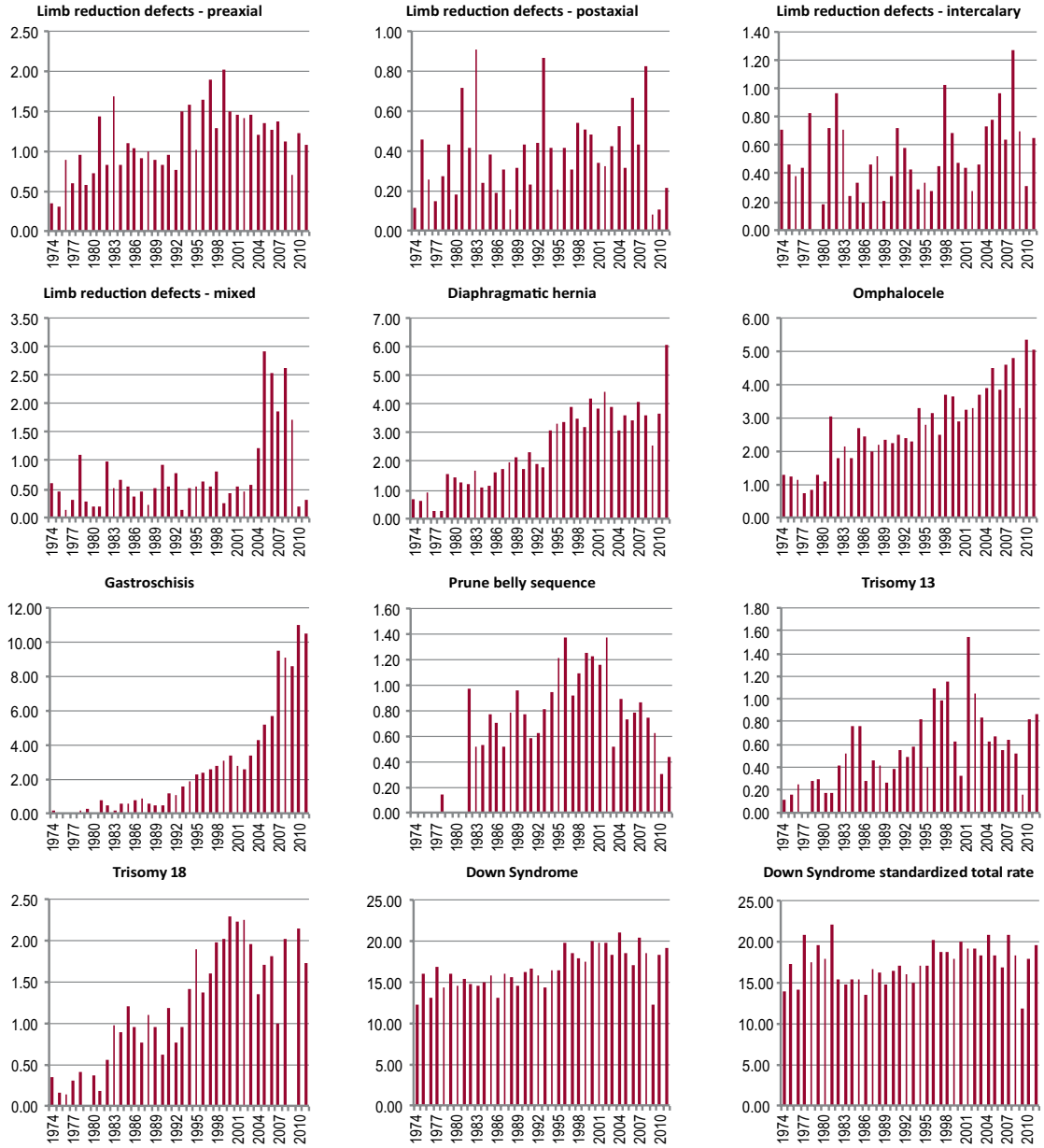
Note: L+S rates, ToP rates

South America: ECLAMC



Note: L+S rates, ToP rates

South America: ECLAMC



Note: L+S rates, ToP 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, although it operates since 1976.

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, and is declared to the Spanish Agency of Data Protection.

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, also 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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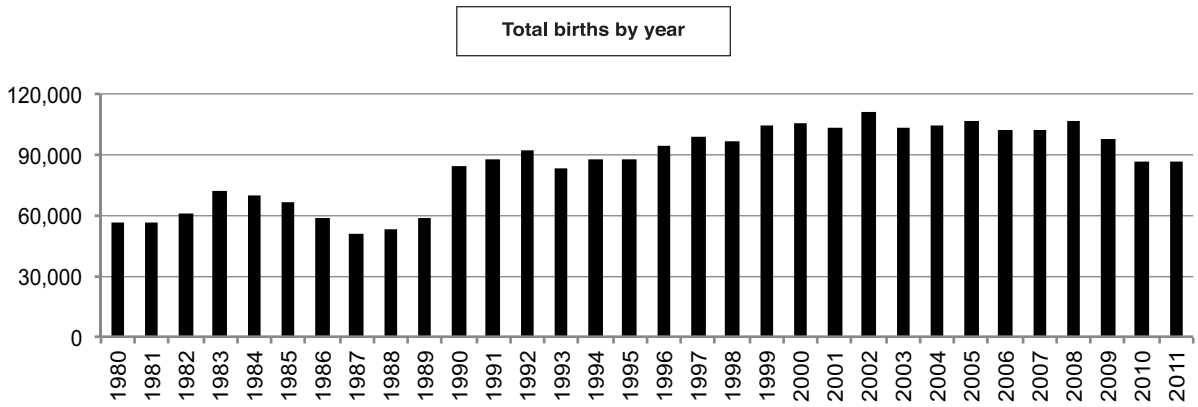
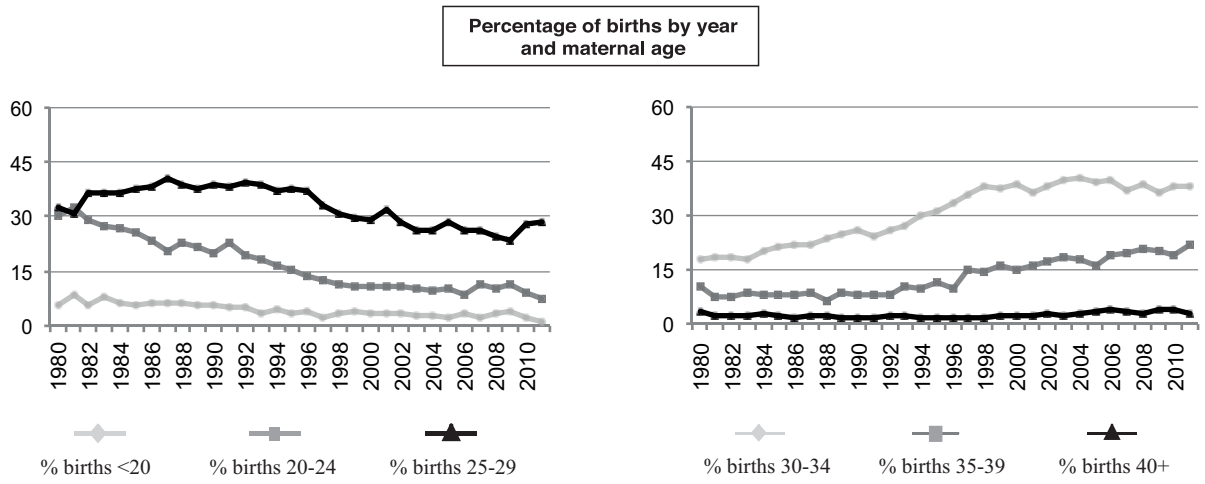
Spain: ECEMC


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
2011


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, 2011

Live births (LB)	86,511
Stillbirths (SB)	289
Total births	86,800
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	1	nr	0.12
Spina bifida	9	0	nr	1.04
Encephalocele	1	0	nr	0.12
Microcephaly	9	0	nr	1.04
Holoprosencephaly	1	0	nr	0.12
Hydrocephaly	14	0	nr	1.61
Anophthalmos	0	0	nr	0.00
Microphthalmos	14	0	nr	1.61
Unspecified Anophthalmos/Microphthalmos	14	0	nr	1.61
Anotia	2	0	nr	0.23
Microtia	12	0	nr	1.38
Unspecified Anotia/Microtia	13	0	nr	1.50
Transposition of great vessels	3	0	nr	0.35
Tetralogy of Fallot	5	0	nr	0.58
Hypoplastic left heart syndrome	1	0	nr	0.12
Coarctation of aorta	5	0	nr	0.58
Choanal atresia, bilateral	1	0	nr	0.12
Cleft palate without cleft lip	27	0	nr	3.11
Cleft lip with or without cleft palate	29	0	nr	3.34
Oesophageal atresia/stenosis with or without fistula	12	0	nr	1.38
Small intestine atresia/stenosis	3	0	nr	0.35
Anorectal atresia/stenosis	13	1	nr	1.61
Undescended testis (36 weeks of gestation or later)	28	0	nr	3.23
Hypospadias	18	0	nr	2.07
Epispadias	1	0	nr	0.12
Indeterminate sex	2	0	nr	0.23
Renal agenesis	2	1	nr	0.35
Cystic kidney	9	0	nr	1.04
Bladder exstrophy	1	0	nr	0.12
Polydactyly, preaxial	19	1	nr	2.30
Total Limb reduction defects (include unspecified)	34	0	nr	3.92
Transverse	13	0	nr	1.50
Preaxial	3	0	nr	0.35
Postaxial	1	0	nr	0.12
Intercalary	1	0	nr	0.12
Mixed	5	0	nr	0.58
Unspecified	9	0	nr	1.04
Diaphragmatic hernia	3	0	nr	0.35
Omphalocele	5	0	nr	0.58
Gastroschisis	4	0	nr	0.46
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	4	0	nr	0.46
Trisomy 13	3	0	nr	0.35
Trisomy 18	4	0	nr	0.46
Down syndrome, all ages (include age unknown)	42	0	nr	4.84
<20	1	0	nr	12.90
20-24	0	0	nr	0.00
25-29	3	0	nr	1.20
30-34	13	0	nr	3.93
35-39	18	0	nr	9.57
40-44	7	0	nr	26.52
45+	0	0	nr	0.00
unknown	0	0	nr	---

nr = data not reported or not available

Spain: ECEMC, Previous years rates 1980 - 2011

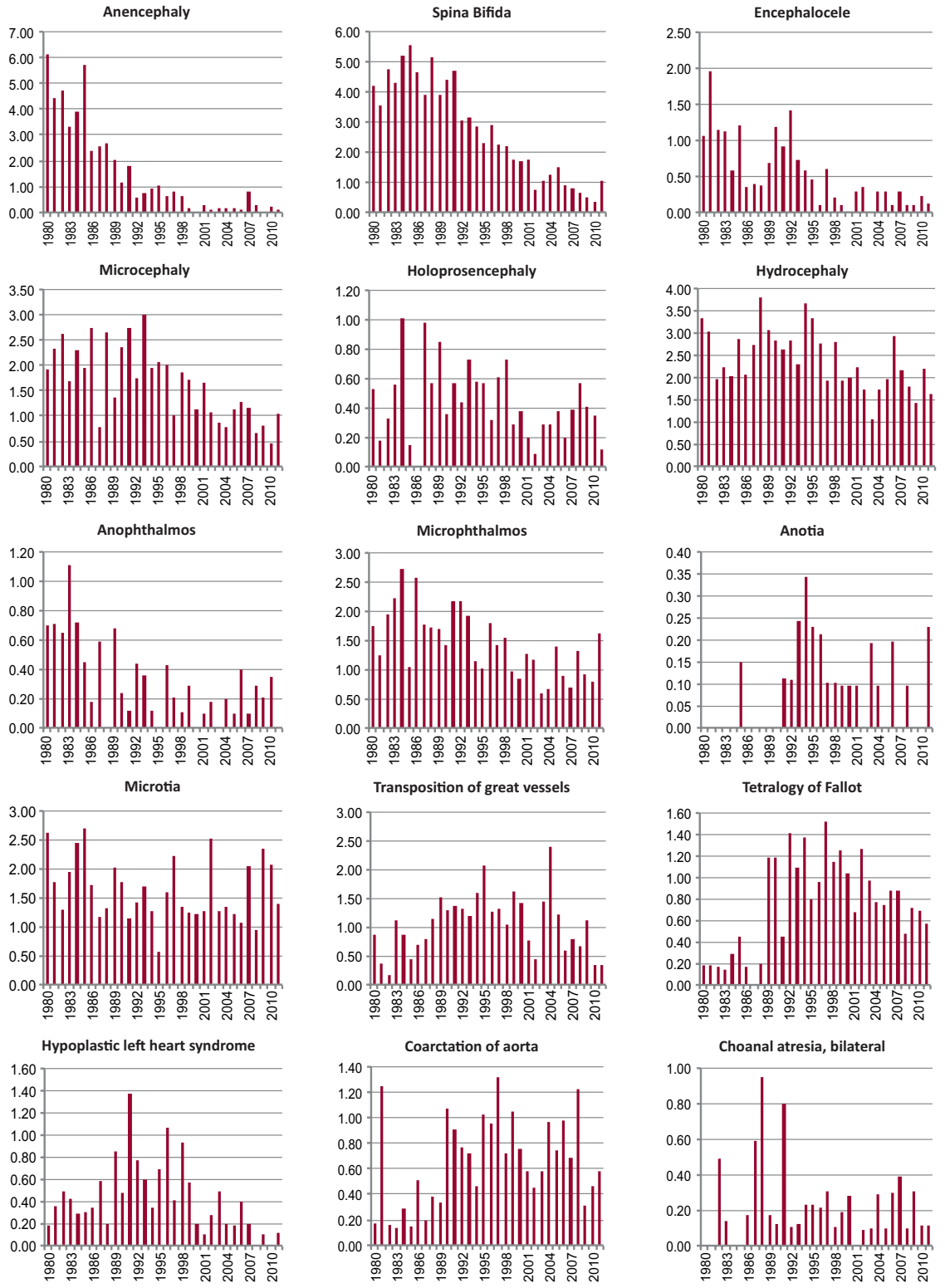
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981*	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births		**113,012**	**327,623**	**334,870**	**443,187**	**509,008**	**526,739**	**480,647**
Anencephaly		5.31	4.03	1.94	0.77	0.37	0.15	0.29
Spina bifida		3.89	4.88	4.42	2.84	1.91	1.08	0.67
Encephalocele		1.50	0.89	0.78	0.65	0.24	0.21	0.17
Microcephaly		2.12	2.23	2.09	2.14	1.47	1.03	0.83
Holoprosencephaly		0.35	0.43	0.63	0.52	0.43	0.25	0.37
Hydrocephaly		3.19	2.23	2.96	2.98	2.16	1.88	1.83
Anophthalmos		0.71	0.64	0.30	0.27	0.14	0.17	0.19
Microphthalmos		1.50	2.11	1.76	1.62	1.20	0.95	1.06
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00	0.29
Anotia		0.00	0.03	0.03	0.23	0.10	0.09	0.06
Microtia		2.21	2.05	1.49	1.31	1.45	1.50	1.75
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00	0.27
Transposition of great vessels		0.62	0.67	1.25	1.49	1.24	1.22	0.67
Tetralogy of Fallot		0.18	0.24	0.66	1.13	1.12	0.93	0.67
Hypoplastic left heart syndrome		0.27	0.37	0.75	0.70	0.43	0.30	0.08
Coarctation of aorta		0.71	0.24	0.66	0.79	0.88	0.74	0.67
Choanal atresia, bilateral		0.00	0.15	0.51	0.18	0.18	0.17	0.21
Cleft palate without cleft lip		4.96	4.91	5.05	4.31	3.79	4.10	3.08
Cleft lip with or without cleft palate		5.93	5.68	5.76	5.26	3.75	3.85	3.06
Oesophageal atresia/stenosis with or without fistula		1.68	2.41	1.85	2.14	1.57	2.13	1.21
Small intestine atresia/stenosis		0.53	0.52	0.57	0.52	0.33	0.63	0.52
Anorectal atresia/stenosis		2.48	2.66	1.97	2.08	2.20	1.92	1.46
Undescended testis (36 weeks of gestation or later)		1.24	2.14	2.66	2.59	3.08	2.11	2.31
Hypospadias		2.65	2.66	2.21	1.69	1.93	1.97	1.62
Epispadias		0.44	0.15	0.30	0.05	0.12	0.06	0.10
Indeterminate sex		0.53	1.16	1.08	0.65	0.67	0.44	0.44
Renal agenesis		0.62	0.73	0.87	0.59	0.26	0.08	0.15
Cystic kidney		1.50	1.13	1.67	1.67	1.69	1.50	1.48
Bladder exstrophy		0.27	0.27	0.27	0.25	0.31	0.15	0.12
Polydactyly, preaxial		2.57	2.38	2.96	2.91	2.65	2.15	1.93
Total Limb reduction defects (include unspecified)		7.52	6.84	7.20	6.54	5.21	4.46	3.97
Transverse		2.83	3.11	3.05	2.19	2.22	1.71	1.71
Preaxial		1.15	1.16	0.93	0.90	0.67	0.57	0.52
Postaxial		0.27	0.09	0.15	0.25	0.18	0.11	0.10
Intercalary		0.53	0.46	0.33	0.59	0.16	0.30	0.15
Mixed		1.50	0.92	1.28	1.08	1.04	0.85	0.75
Unspecified		1.24	1.10	1.46	1.53	0.90	0.49	0.71
Diaphragmatic hernia		2.48	2.56	2.21	2.08	1.12	0.66	0.98
Omphalocele		2.12	1.50	1.49	1.02	0.61	0.55	0.56
Gastroschisis		0.80	0.40	0.48	0.36	0.41	0.46	0.60
Unspecified Omphalocele/Gastroschisis		0.27	0.37	0.33	0.09	0.06	0.02	0.02
Prune belly sequence		0.44	0.58	0.66	0.41	0.20	0.21	0.27
Trisomy 13		0.27	0.37	0.48	0.45	0.47	0.36	0.23
Trisomy 18		0.44	1.34	0.90	0.81	0.67	0.61	0.58
Down syndrome, all ages (include age unknown)		14.60	15.02	13.92	11.76	9.80	7.35	6.80
<20		8.72	7.08	10.76	3.34	1.18	3.83	6.12
20-24		8.44	5.86	5.27	5.69	4.72	5.20	3.30
25-29		5.33	7.23	8.17	6.55	6.11	3.85	2.55
30-34		12.31	11.74	14.28	12.88	9.03	6.55	4.77
35-39		40.80	48.10	39.94	32.58	17.72	11.65	12.48
40-44		117.61	189.43	129.80	51.00	52.03	31.95	33.45
45+		163.27	246.91	137.93	265.49	2666.67	42.55	112.57
unknown		---	---	---	---	---	---	---

* data include less than 5 years

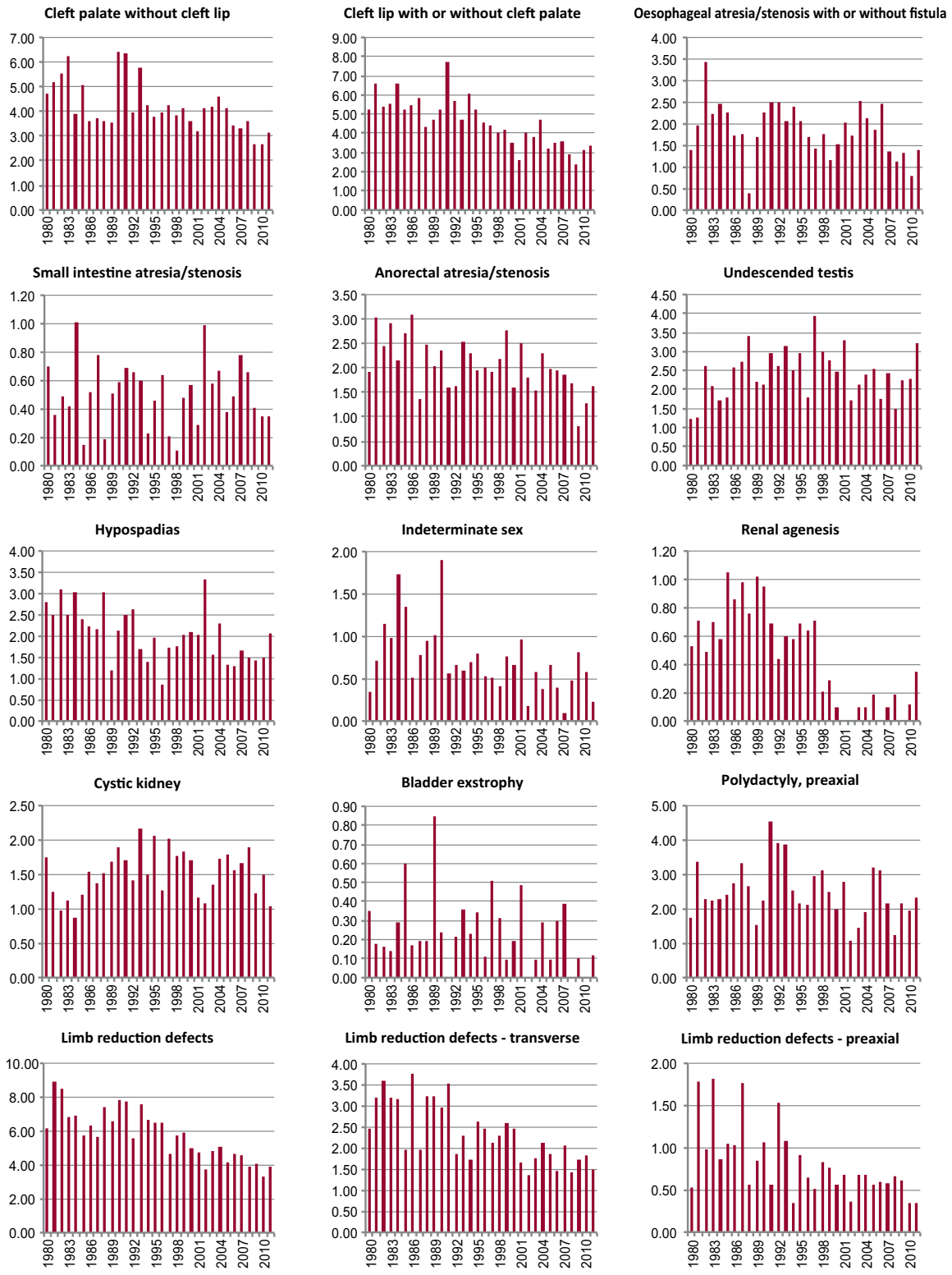
Spain: ECEMC

Time trends 1980-2011 (Birth prevalence rates per 10,000)



Note: L+S rates

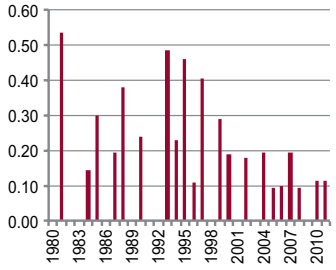
Spain: ECEMC



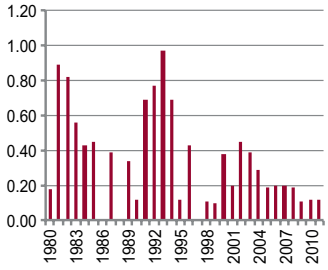
Note: L+S rates

Spain: ECEMC

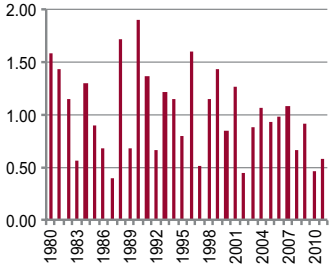
Limb reduction defects - postaxial



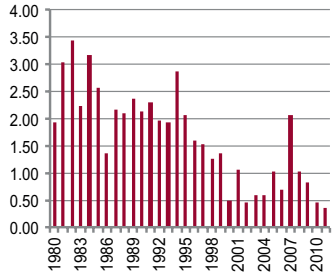
Limb reduction defects - intercalary



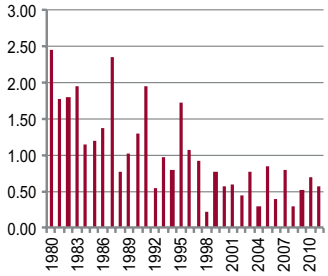
Limb reduction defects - mixed



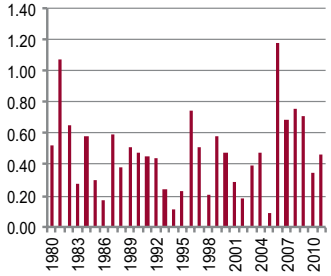
Diaphragmatic hernia



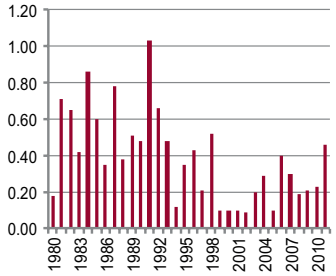
Omphalocele



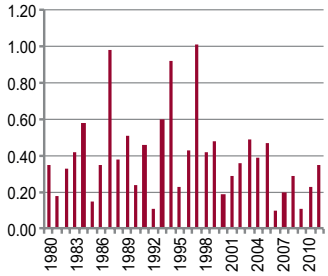
Gastroschisis



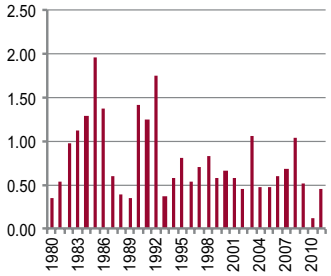
Prune belly sequence



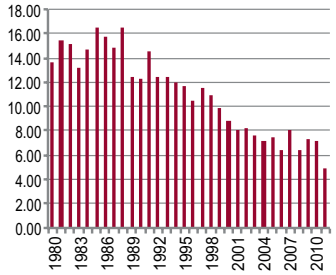
Trisomy 13



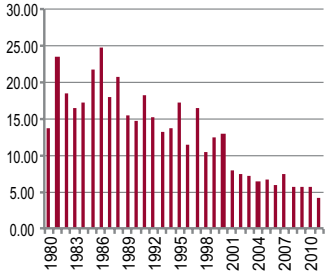
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Sweden

The Swedish Birth Defects Register 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).

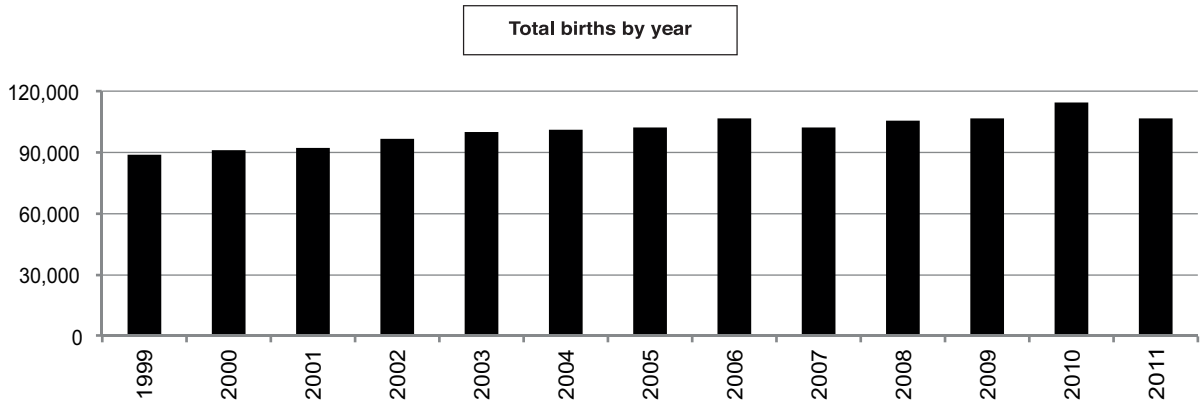
Sources of ascertainment:
Reports are received from delivery units, paediatric clinics, pathology departments, child cardiology clinics, and cytogenetic laboratories.

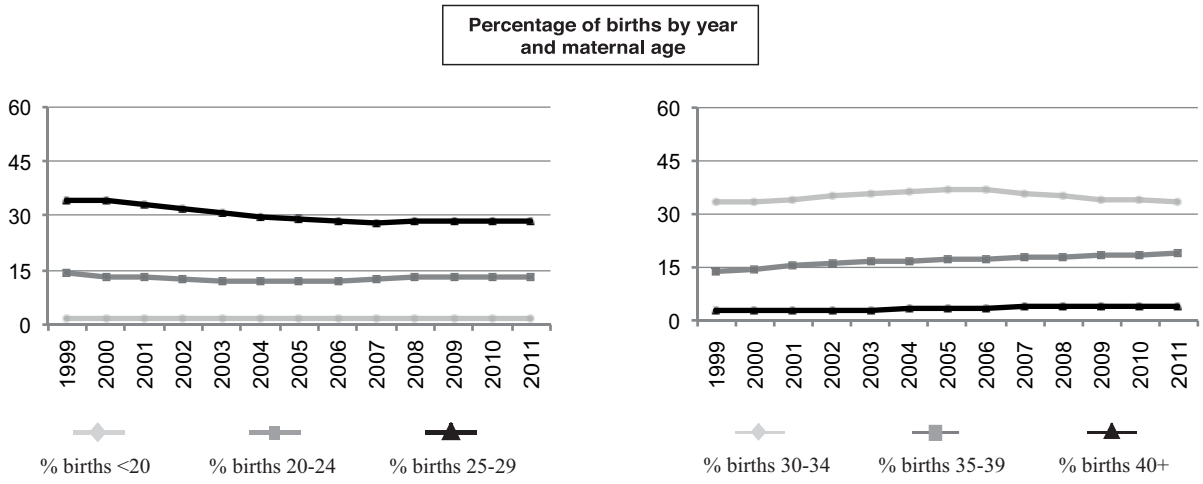
Exposure information:
Some exposure information for all births is available in the Medical Birth Registry: maternal occupation, civic status, maternal smoking, drug use during pregnancy, contraceptive usage, and maternal diseases.

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 (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	70	92.1	Cystic kidney	39	37.5
Spina bifida	69	65.7	Limb reduction defects	30	18.5
Encephalocele	13	56.5	Diaphragmatic hernia	27	33.3
Holoprosencephaly	13	81.3	Omphalocele	43	64.2
Hydrocephaly	46	57.5	Gastroschisis	9	16.1
Hypoplastic left heart syndrome	38	61.3	Trisomy 13	104	86.0
Cleft palate without cleft lip	8	4.4	Trisomy 18	275	87.0
Cleft lip with or without cleft palate	6	4.9	Down syndrome	668	60.1
Renal agenesis	21	31.8			

Total ToPs with births defects = 1,865 (Ratio ToPs/Births: 5.70 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Sweden, 2011

Live births (LB)	105,819
Stillbirths (SB)	369
Total births	106,188
Number of terminations of pregnancy (ToP) for birth defects	586

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	18	1.79
Spina bifida	10	0	22	3.01
Encephalocele	4	0	4	0.75
Microcephaly	3	0	2	0.47
Holoprosencephaly	2	0	4	0.57
Hydrocephaly	10	0	13	2.17
Anophthalmos	2	0	1	0.28
Microphthalmos	4	0	0	0.38
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	7	0	0	0.66
Microtia	7	0	0	0.66
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	22	0	2	2.26
Tetralogy of Fallot	29	0	2	2.92
Hypoplastic left heart syndrome	7	0	13	1.88
Coarctation of aorta	30	0	2	3.01
Choanal atresia, bilateral	2	0	0	0.19
Cleft palate without cleft lip	61	0	2	5.93
Cleft lip with or without cleft palate	1	9	0	0.94
Oesophageal atresia/stenosis with or without fistula	35	1	1	3.48
Small intestine atresia/stenosis	32	1	0	3.11
Anorectal atresia/stenosis	32	0	2	3.20
Undescended testis (36 weeks of gestation or later)	16	0	0	1.51
Hypospadias	281	0	2	26.65
Epispadias	2	0	0	0.19
Indeterminate sex	5	0	0	0.47
Renal agenesis	21	0	8	2.73
Cystic kidney	21	0	13	3.20
Bladder exstrophy	1	0	1	0.19
Polydactyly, preaxial	19	0	0	1.79
Total Limb reduction defects (include unspecified)	39	1	12	4.90
Transverse	21	0	4	nr
Preaxial	9	0	1	nr
Postaxial	2	0	1	nr
Intercalary	1	0	1	nr
Mixed	13	1	6	nr
Unspecified	0	0	0	nr
Diaphragmatic hernia	16	1	10	2.54
Omphalocele	8	0	12	1.88
Gastroschisis	19	0	1	1.88
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	3	0.28
Trisomy 13	2	1	30	3.11
Trisomy 18	8	1	83	8.66
Down syndrome, all ages (include age unknown)	134	0	206	32.02
<20	1	0	1	11.96
20-24	3	0	4	4.92
25-29	11	0	7	5.95
30-34	31	0	27	16.24
35-39	55	0	75	65.20
40-44	24	0	79	248.49
45+	7	0	12	829.69
unknown	2	0	1	---

nr = data not reported or not available

Sweden, Previous years rates 1999 - 2011

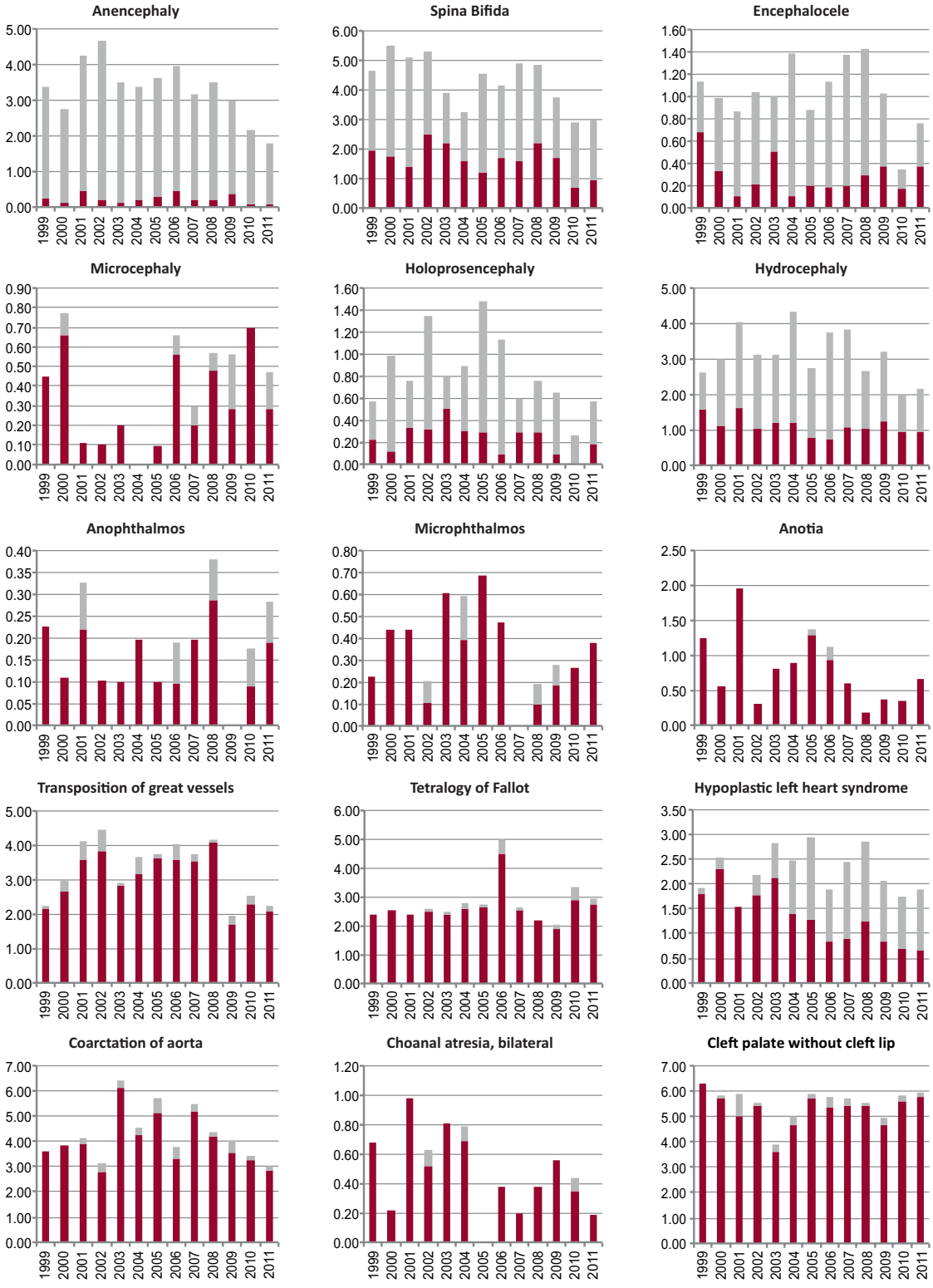
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001*	2002-2006	2007-2011
Total births						**271,123**	**504,823**	**534,372**
Anencephaly						3.47	3.82	2.71
Spina bifida						5.09	4.22	3.85
Encephalocele						1.00	1.09	0.97
Microcephaly						0.44	0.22	0.52
Holoprosencephaly						0.77	1.13	0.56
Hydrocephaly						3.21	3.43	2.75
Anophthalmos						0.22	0.14	0.21
Microphthalmos						0.37	0.52	0.22
Unspecified Anophthalmos/Microphthalmos						0.00	0.00	0.07
Anotia						1.25	0.91	0.43
Microtia						0.07	0.18	0.37
Unspecified Anotia/Microtia						0.00	0.00	0.06
Transposition of great vessels						3.14	3.76	2.92
Tetralogy of Fallot						2.43	3.15	2.64
Hypoplastic left heart syndrome						1.99	2.46	2.19
Coarctation of aorta						3.87	4.71	4.04
Choanal atresia, bilateral						0.63	0.52	0.36
Cleft palate without cleft lip						6.01	5.23	5.60
Cleft lip with or without cleft palate						9.55	10.66	4.10
Oesophageal atresia/stenosis with or without fistula						2.14	2.61	2.66
Small intestine atresia/stenosis						1.99	2.87	1.89
Anorectal atresia/stenosis						2.77	2.95	3.07
Undescended testis (36 weeks of gestation or later)						nr	nr	0.62
Hypospadias						20.47	21.16	23.86
Epispadias						0.15	0.20	0.28
Indeterminate sex						0.22	0.28	0.22
Renal agenesis						2.47	1.09	2.19
Cystic kidney						2.91	3.64	3.20
Bladder exstrophy						0.18	0.30	0.26
Polydactyly, preaxial						4.09	5.13	1.59
Total Limb reduction defects (include unspecified)						4.46	5.25	4.83
Transverse						2.88	3.57	2.79
Preaxial						0.22	0.40	0.51
Postaxial						0.18	0.12	0.21
Intercalary						0.15	0.26	0.26
Mixed						1.03	0.52	1.27
Unspecified						0.00	0.00	1.07
Diaphragmatic hernia						2.69	2.93	2.84
Omphalocele						2.36	2.83	1.95
Gastroschisis						2.03	1.74	1.68
Unspecified Omphalocele/Gastroschisis						0.00	0.00	0.00
Prune belly sequence						0.07	0.12	0.24
Trisomy 13						2.03	2.75	3.48
Trisomy 18						5.79	7.31	9.00
Down syndrome, all ages (include age unknown)						22.90	26.31	31.70
<20						7.86	10.75	9.04
20-24						8.24	10.06	6.85
25-29						8.29	9.74	8.94
30-34						15.57	18.28	16.31
35-39						53.49	56.48	61.54
40-44						167.18	171.21	246.19
45+						500.00	402.58	822.72
unknown						---	---	---

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

Sweden

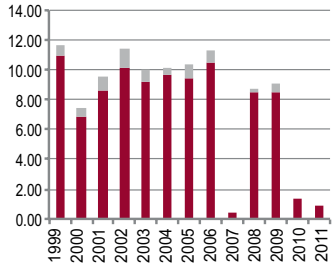
Time trends 1999-2011 (Birth prevalence rates per 10,000)



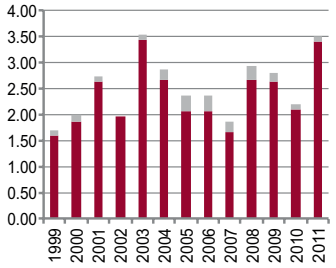
Note: L+S rates, ToP rates

Sweden

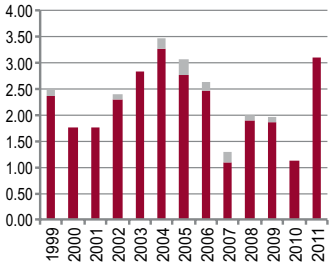
Cleft lip with or without cleft palate



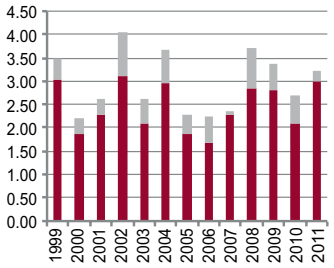
Oesophageal atresia/stenosis with or without fistula



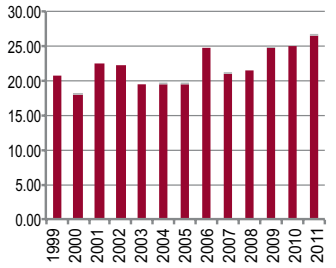
Small intestine atresia/stenosis



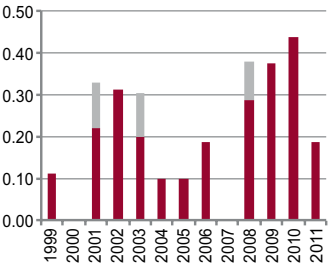
Anorectal atresia/stenosis



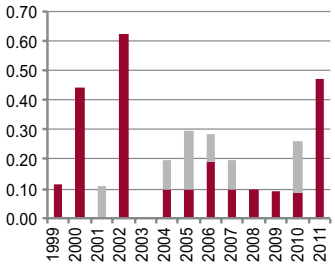
Hypospadias



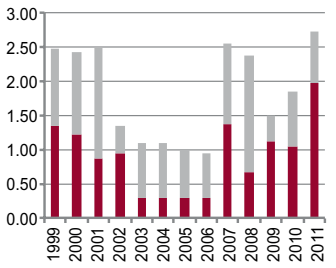
Epispadias



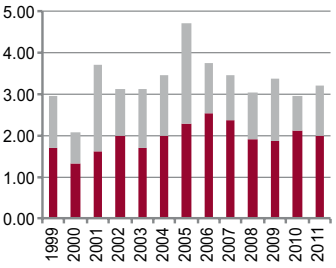
Indeterminate sex



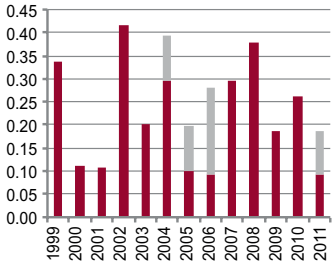
Renal agenesis



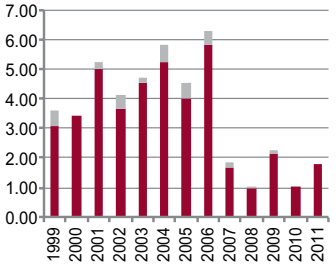
Cystic kidney



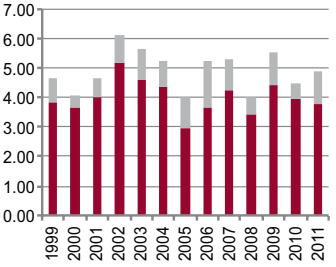
Bladder exstrophy



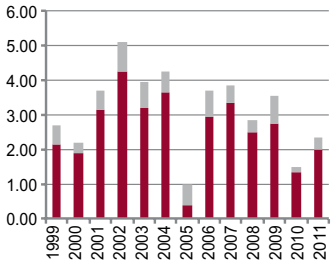
Polydactyly, preaxial



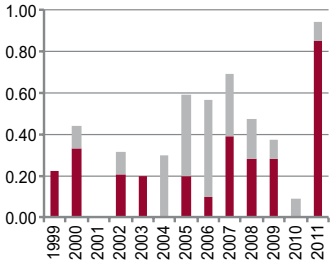
Limb reduction defects



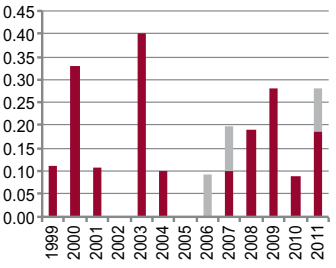
Limb reduction defects - transverse



Limb reduction defects - preaxial



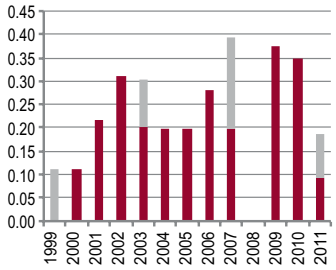
Limb reduction defects - postaxial



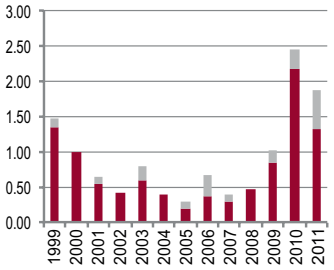
Note: L+S rates, ToP rates

Sweden

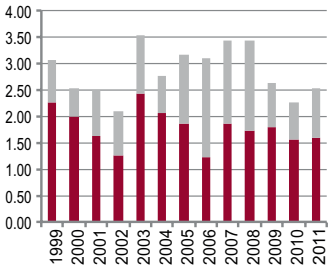
Limb reduction defects - intercalary



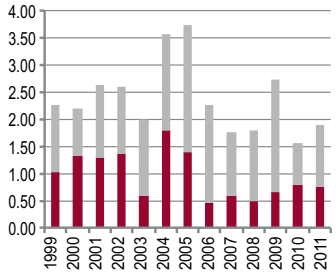
Limb reduction defects - mixed



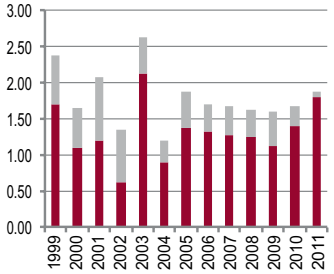
Diaphragmatic hernia



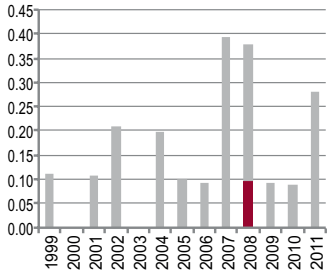
Omphalocele



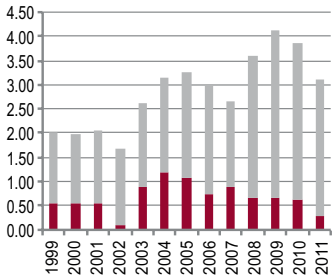
Gastroschisis



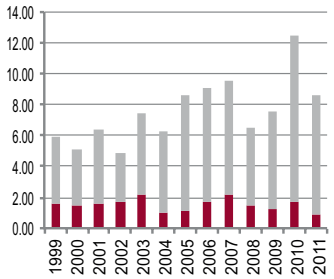
Prune belly sequence



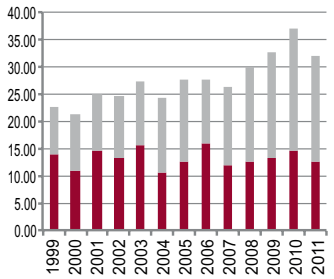
Trisomy 13



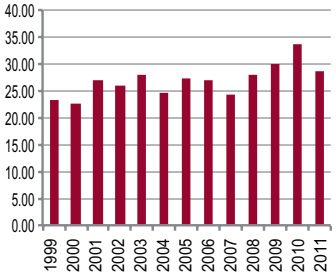
Trisomy 18



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.

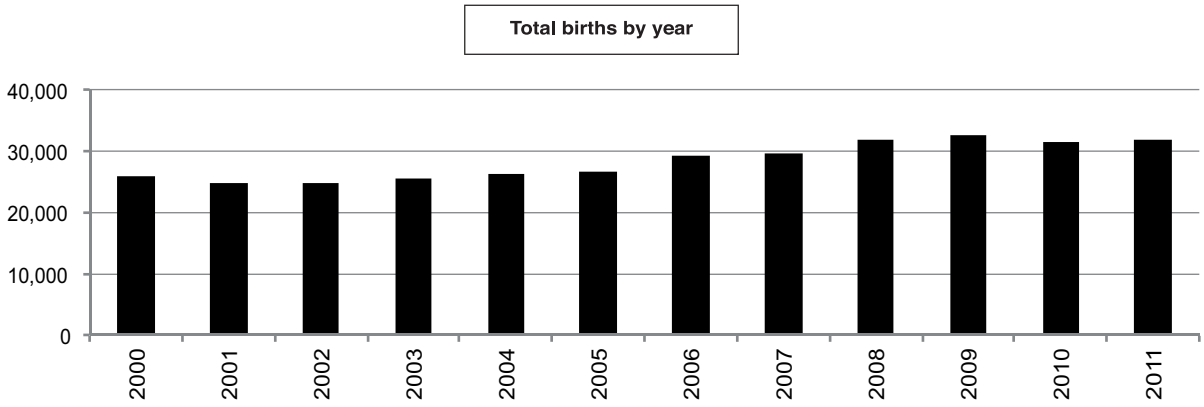
Exposure information:
Routine information collection is limited except when ad hoc circumstances are noted. An expansion of exposure data collection is in progress.

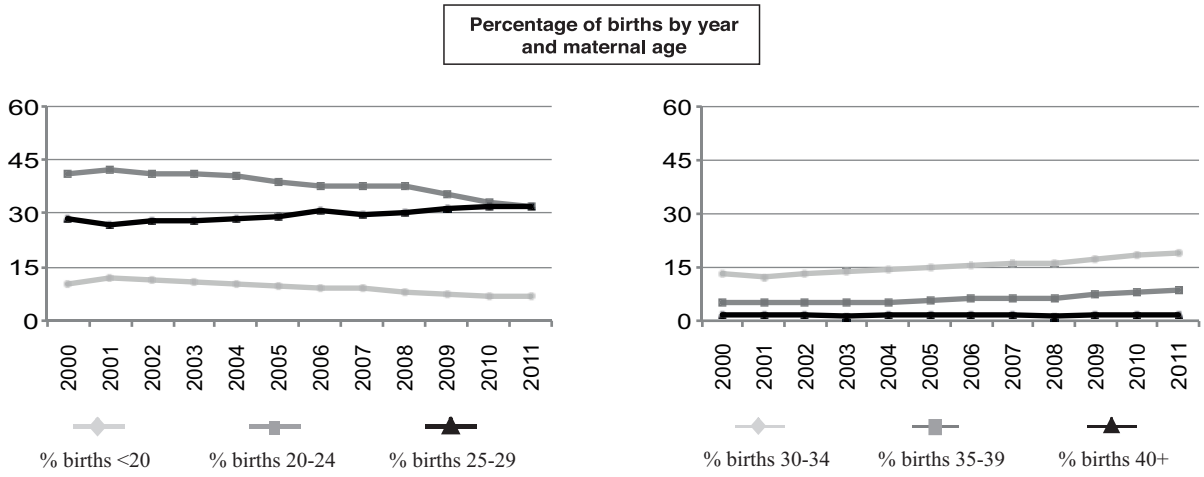
Prenatal diagnosis information:
The information is substantial regarding service providers located in regional centers, but limited regarding service providers in rural environment.

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:
Program Director: Dr. Wladimir Wertelecki
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, 2011

Live births (LB)	31,634
Stillbirths (SB)	183
Total births	31,817
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP(1)	Total rate
Anencephaly	0	4	16	6.29
Spina bifida	22	1	18	12.89
Encephalocele	1	0	5	1.89
Microcephaly	19	1	nr	6.29
Holoprosencephaly(2)	4	2	nr	1.89
Hydrocephaly	13	1	nr	4.40
Anophthalmos	1	0	nr	0.31
Microphthalmos(2)	3	0	nr	0.94
Unspecified Anophthalmos/Microphthalmos(2)	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	6	0	nr	1.89
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	13	0	nr	4.09
Tetralogy of Fallot	4	0	nr	1.26
Hypoplastic left heart syndrome	12	1	nr	4.09
Coarctation of aorta	7	0	nr	2.20
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	25	0	nr	7.86
Cleft lip with or without cleft palate	22	0	nr	6.91
Oesophageal atresia/stenosis with or without fistula	8	0	nr	2.51
Small intestine atresia/stenosis	4	1	nr	1.57
Anorectal atresia/stenosis	10	0	nr	3.14
Undescended testis (36 weeks of gestation or later)	113	0	nr	35.52
Hypospadias(3)	9	0	nr	2.83
Epispadias	0	0	nr	0.00
Indeterminate sex	1	0	nr	0.31
Renal agenesis	3	0	nr	0.94
Cystic kidney	13	1	nr	4.40
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	12	0	nr	3.77
Total Limb reduction defects (include unspecified)	18	0	nr	5.66
Transverse	10	0	nr	3.14
Preaxial	2	0	nr	0.63
Postaxial	0	0	nr	0.00
Intercalary	1	0	nr	0.31
Mixed	1	0	nr	0.31
Unspecified	0	0	nr	0.00
Diaphragmatic hernia	6	2	nr	2.51
Omphalocele	2	1	nr	0.94
Gastroschisis	2	0	nr	0.63
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13(4)	0	0	nr	0.00
Trisomy 18(5)	1	0	nr	0.31
Down syndrome, all ages (include age unknown)(2,6)	57	0	nr	17.91
<20	0	0	nr	0.00
20-24	8	0	nr	7.87
25-29	10	0	nr	9.83
30-34	16	0	nr	26.11
35-39	8	0	nr	30.18
40-44	14	0	nr	243.48
45+	1	0	nr	357.14
unknown	0	0	nr	---

nr = data not reported or not available
(1) Number of terminations of pregnancy (ToP) for birth defects is not reported, except for NTD;
(2) Clinical diagnosis only; with photodocumentation or measurements documented;
(3) Includes penile, scrotal, and perineal hypospadias only;
(4) Two ToPs with Trisomy 13 confirmed by amniocentesis
(5) One ToP with Trisomy 18 confirmed by amniocentesis
(6) Six ToPs with Down Syndrome confirmed by amniocentesis

Ukraine: OMNI-Net, Previous years rates 2000 - 2011

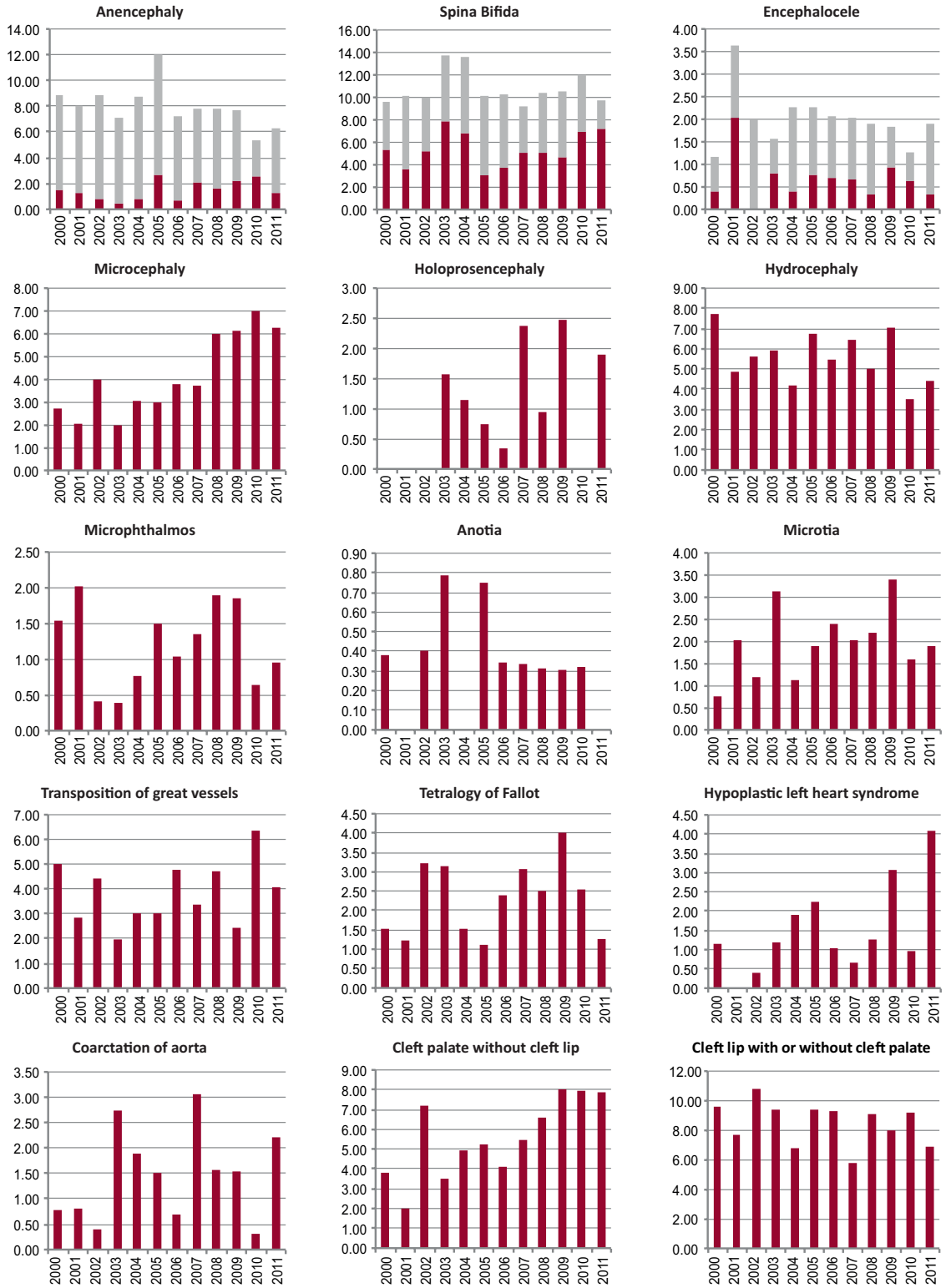
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001*	2002-2006	2007-2011
Total births						**50,771**	**132,575**	**157,170**
Anencephaly						8.47	8.75	7.00
Spina bifida						9.85	11.54	10.37
Encephalocele						2.36	2.04	1.78
Microcephaly						2.36	3.17	5.85
Holoprosencephaly						0.00	0.75	1.53
Hydrocephaly						6.30	5.58	5.28
Anophthalmos						0.20	0.00	0.25
Microphthalmos						1.77	0.83	1.34
Unspecified Anophthalmos/Microphthalmos						0.00	0.00	0.06
Anotia						0.20	0.45	0.25
Microtia						1.38	1.96	2.23
Unspecified Anotia/Microtia						0.00	0.00	0.00
Transposition of great vessels						3.94	3.47	4.20
Tetralogy of Fallot						1.38	2.26	2.67
Hypoplastic left heart syndrome						0.59	1.36	2.04
Coarctation of aorta						0.79	1.43	1.72
Choanal atresia, bilateral						0.00	0.00	0.06
Cleft palate without cleft lip						2.95	4.98	7.19
Cleft lip with or without cleft palate						8.67	9.13	7.83
Oesophageal atresia/stenosis with or without fistula						1.77	1.96	2.23
Small intestine atresia/stenosis						1.38	1.58	1.53
Anorectal atresia/stenosis						2.36	2.41	2.16
Undescended testis (36 weeks of gestation or later)						36.64	41.71	31.56
Hypospadias						3.55	3.32	2.80
Epispadias						0.59	0.15	0.06
Indeterminate sex						0.59	0.45	0.25
Renal agenesis						0.79	0.75	0.89
Cystic kidney						0.98	2.87	4.77
Bladder exstrophy						0.79	0.75	0.38
Polydactyly, preaxial						2.76	3.62	4.14
Total Limb reduction defects (include unspecified)						4.33	3.02	4.84
Transverse						2.56	1.66	3.05
Preaxial						0.39	0.45	0.51
Postaxial						0.59	0.15	0.25
Intercalary						0.39	0.30	0.25
Mixed						0.20	0.23	0.45
Unspecified						0.20	0.23	0.00
Diaphragmatic hernia						2.17	1.66	2.93
Omphalocele						0.98	1.36	1.97
Gastroschisis						0.59	1.66	1.34
Unspecified Omphalocele/Gastroschisis						0.00	0.00	0.00
Prune belly sequence						0.00	0.00	0.00
Trisomy 13						0.20	0.38	0.13
Trisomy 18						0.59	0.23	0.45
Down syndrome, all ages (include age unknown)						10.83	13.50	14.38
<20						8.86	10.38	6.77
20-24						5.66	7.59	7.08
25-29						7.84	9.95	9.81
30-34						15.49	15.15	17.54
35-39						15.10	43.28	35.27
40-44						136.61	112.23	160.89
45+						638.30	666.67	259.74
unknown						---	---	---

* data include less than 5 years

Ukraine: OMNI-Net

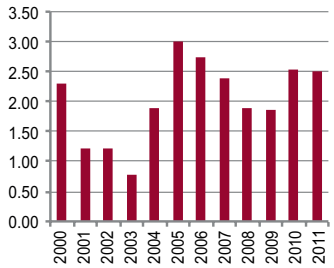
Time trends 2000-2011 (Birth prevalence rates per 10,000)



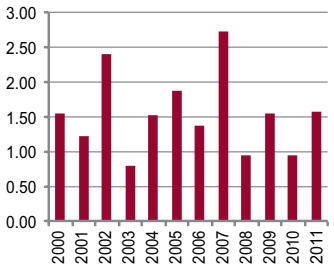
Note: L+S rates, ToP rates

Ukraine: OMNI-Net

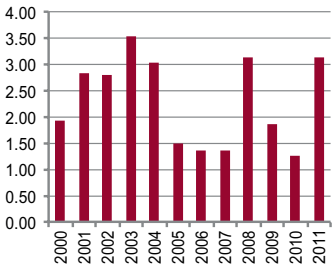
Oesophageal atresia/stenosis with or without fistula



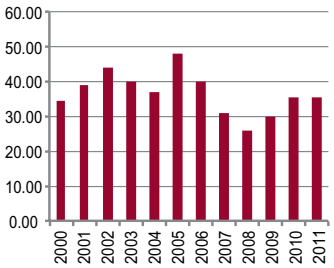
Small intestine atresia/stenosis



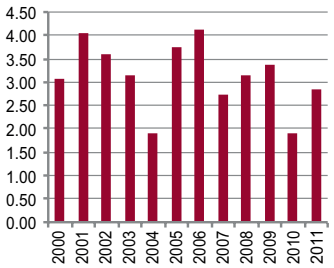
Anorectal atresia/stenosis



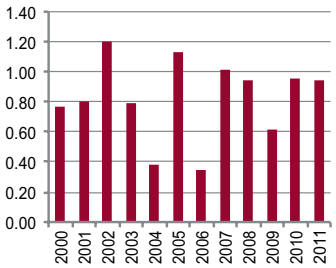
Undescended testis



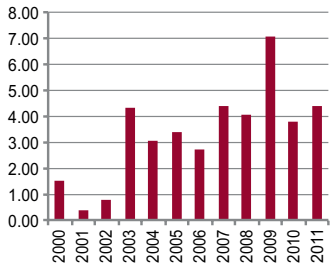
Hypospadias



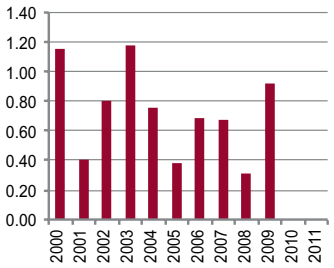
Renal agenesis



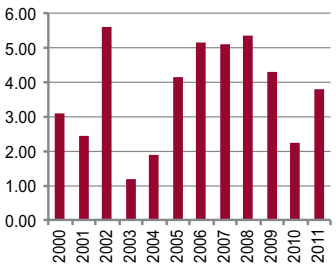
Cystic kidney



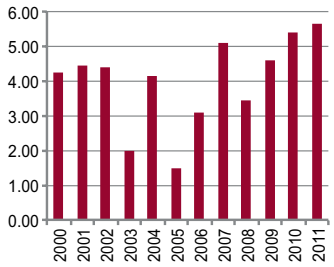
Bladder exstrophy



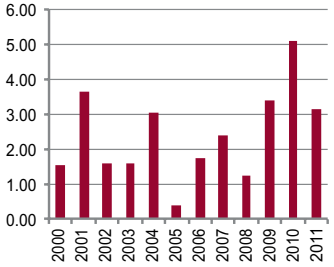
Polydactyly, preaxial



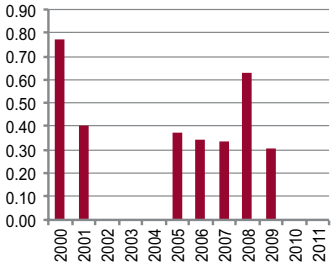
Limb reduction defects



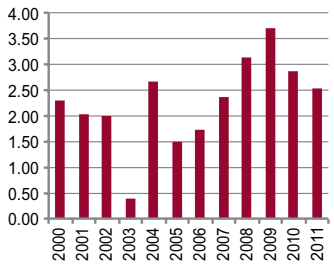
Limb reduction defects - transverse



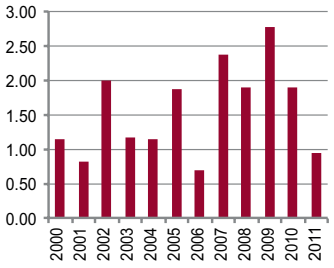
Limb reduction defects - postaxial



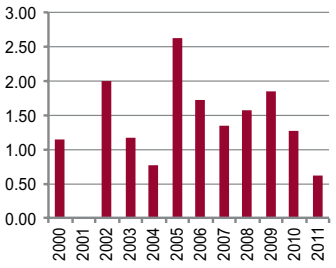
Diaphragmatic hernia



Omphalocele

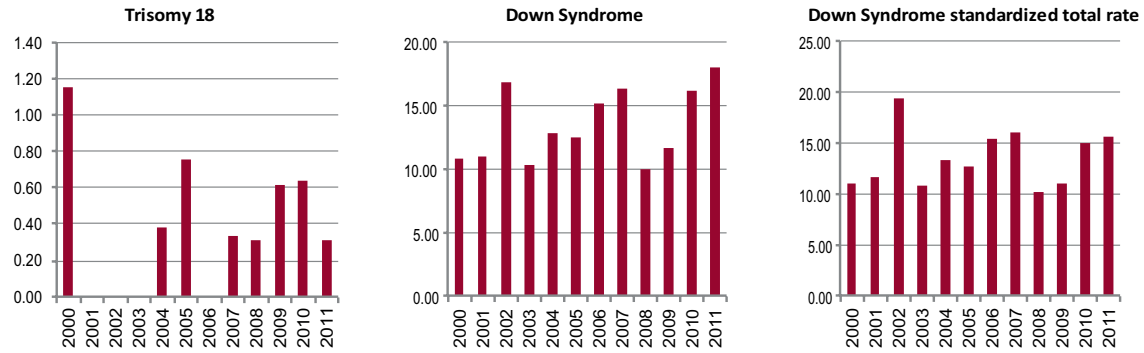


Gastroschisis



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:
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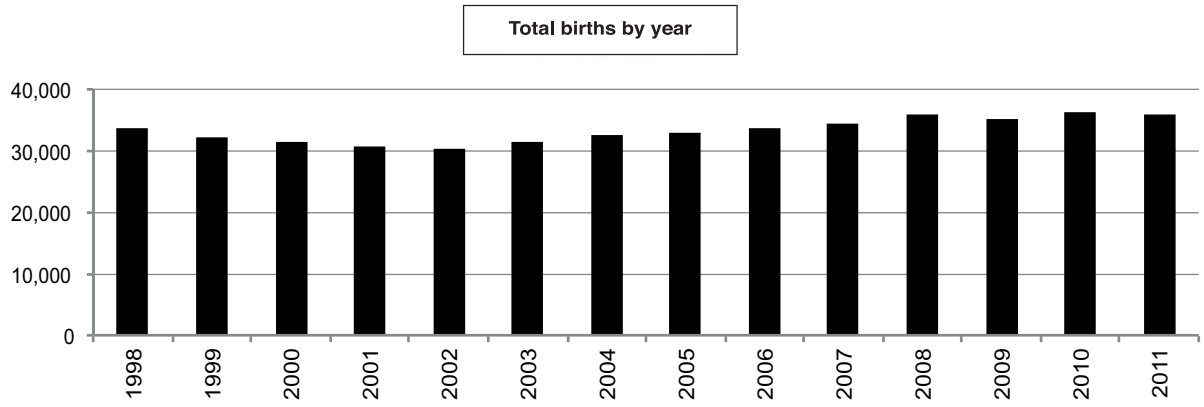
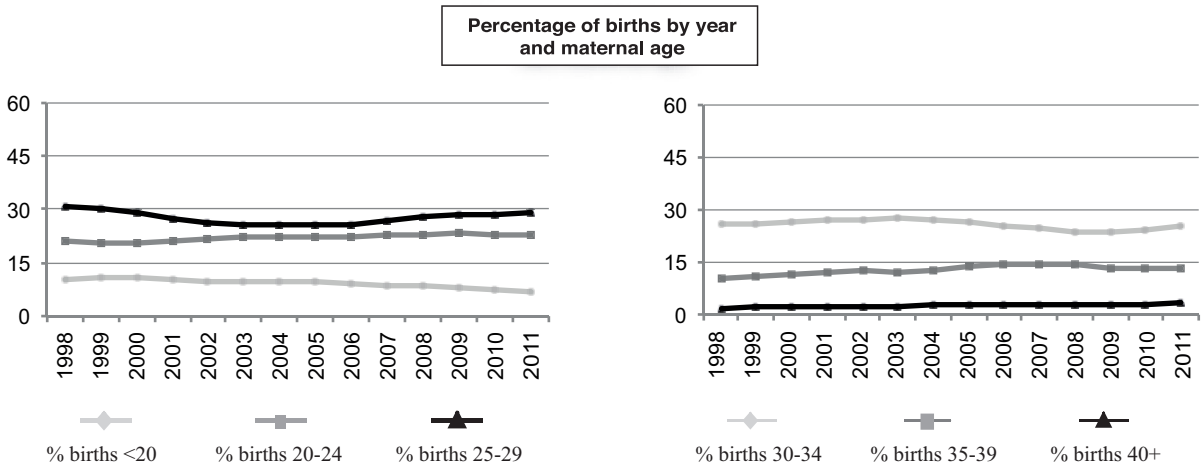
Phone: 44-1792-285241
Fax: 44-1792-285241

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

United Kingdom-Wales: CARIS





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	59	100.0	Cystic kidney	15	20.5
Spina bifida	54	62.8	Limb reduction defects	26	34.7
Encephalocele	19	82.6	Diaphragmatic hernia	13	31.7
Holoprosencephaly	7	70.0	Omphalocele	24	53.3
Hydrocephaly	34	43.6	Gastroschisis	5	8.9
Hypoplastic left heart syndrome	12	50.0	Trisomy 13	17	85.0
Cleft palate without cleft lip	6	6.7	Trisomy 18	50	80.6
Cleft lip with or without cleft palate	14	14.4	Down syndrome	132	51.4
Renal agenesis	14	87.5			

Total ToPs with births defects = 538 (Ratio ToPs/Births: 5.03 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

United Kingdom-Wales: CARIS, 2011

Live births (LB)	35,598
Stillbirths (SB)	167
Total births	35,765
Number of terminations of pregnancy (ToP) for birth defects	187

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	19	5.31
Spina bifida	8	0	19	7.55
Encephalocele	≤3	0	4	nc
Microcephaly	7	0	≤3	nc
Holoprosencephaly	≤3	0	≤3	nc
Hydrocephaly	11	0	12	6.43
Anophthalmos	0	0	0	0.00
Microphthalmos	5	0	0	1.40
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.84
Microtia	5	0	0	1.40
Unspecified Anotia/Microtia	≤3	0	0	nc
Transposition of great vessels	12	0	6	5.03
Tetralogy of Fallot	11	0	≤3	nc
Hypoplastic left heart syndrome	4	0	5	2.52
Coarctation of aorta	15	0	0	4.19
Choanal atresia, bilateral	3	0	0	0.84
Cleft palate without cleft lip	31	0	≤3	nc
Cleft lip with or without cleft palate	16	≤3	0	nc
Oesophageal atresia/stenosis with or without fistula	10	≤3	≤3	nc
Small intestine atresia/stenosis	4	0	0	1.12
Anorectal atresia/stenosis	11	0	≤3	nc
Undescended testis (36 weeks of gestation or later)	53	0	0	14.82
Hypospadias	89	0	0	24.88
Epispadias	≤3	0	0	nc
Indeterminate sex	0	0	0	0.00
Renal agenesis	≤3	0	≤3	nc
Cystic kidney	17	0	5	6.15
Bladder exstrophy	2	0	0	0.56
Polydactyly, preaxial	2	0	0	0.56
Total Limb reduction defects (include unspecified)	11	0	5	4.47
Transverse	7	0	5	nr
Preaxial	3	0	0	nr
Postaxial	0	0	0	nr
Intercalary	≤3	0	0	nr
Mixed	0	0	0	nr
Unspecified	0	0	0	nr
Diaphragmatic hernia	7	0	5	3.36
Omphalocele	8	≤3	7	nc
Gastroschisis	14	0	3	4.75
Unspecified Omphalocele/Gastroschisis	0	0	≤3	nc
Prune belly sequence	0	0	0	0.00
Trisomy 13	≤3	0	4	nc
Trisomy 18	≤3	0	13	nc
Down syndrome, all ages (include age unknown)	40	≤3	48	nc
<20	3	0	≤3	nc
20-24	5	0	4	11.09
25-29	8	0	4	11.59
30-34	5	≤3	12	nc
35-39	12	0	14	56.07
40-44	5	0	12	161.44
45+	≤3	0	≤3	nc
unknown	0	0	0	---

nr = data not reported or not available
Wales policy on publishing small numbers: numbers less than 3 cannot be shown to protect patient confidentiality

United Kingdom-Wales: CARIS, Previous years rates 1998 - 2011

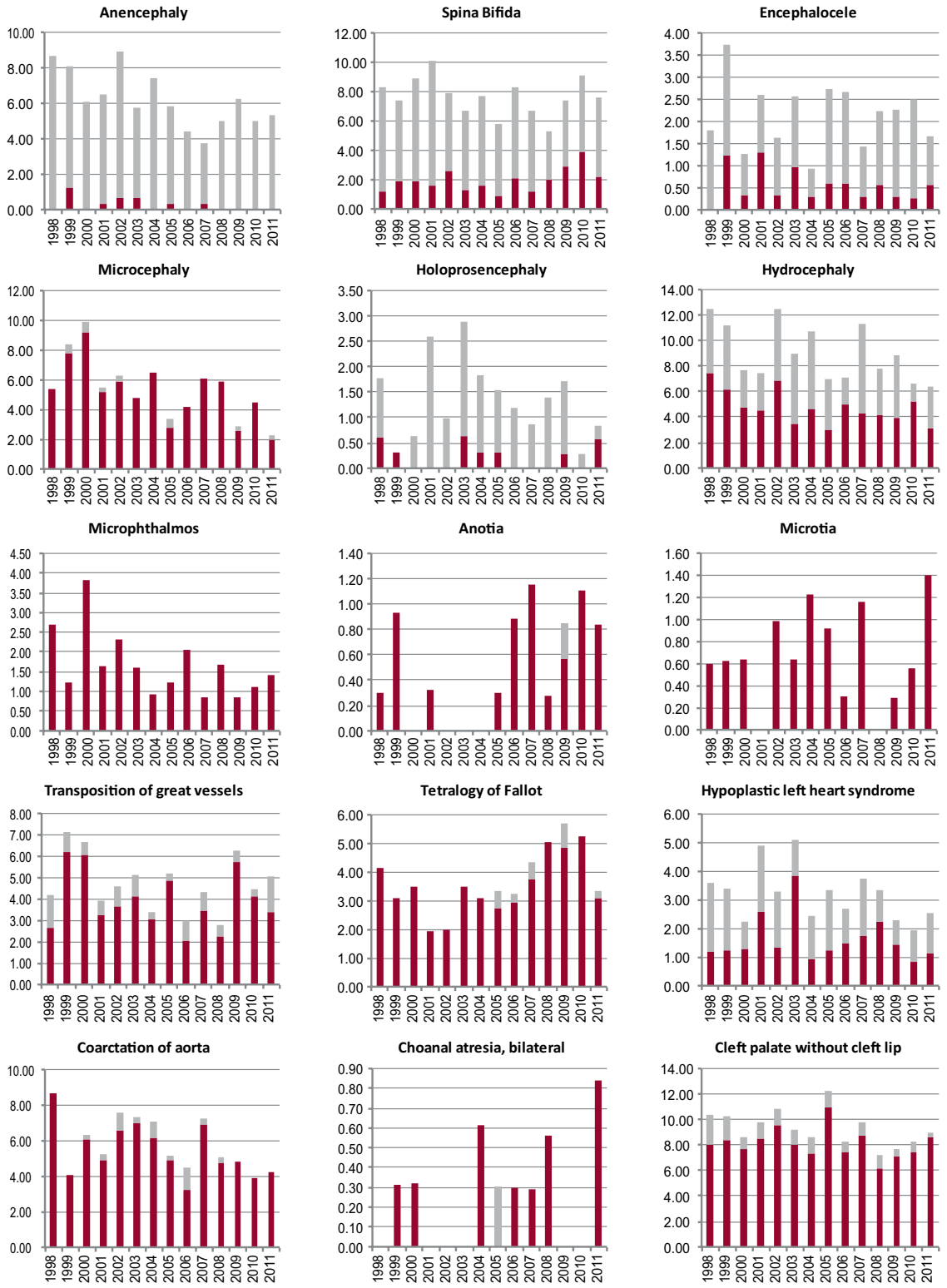
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001*	2002-2006	2007-2011
Total births								
Anencephaly						7.34	6.41	5.07
Spina bifida						8.66	7.28	7.21
Encephalocele						2.34	2.12	2.03
Microcephaly						7.26	4.98	4.28
Holoprosencephaly						1.33	1.68	1.01
Hydrocephaly						9.76	9.21	8.17
Anophthalmos						0.62	0.25	0.00
Microphthalmos						2.34	1.62	1.18
Unspecified Anophthalmos/Microphthalmos						0.00	0.00	0.00
Anotia						0.39	0.25	0.85
Microtia						0.47	0.81	0.68
Unspecified Anotia/Microtia						0.00	0.00	0.06
Transposition of great vessels						5.46	4.23	4.57
Tetralogy of Fallot						3.20	3.05	4.73
Hypoplastic left heart syndrome						3.51	3.36	2.76
Coarctation of aorta						6.09	6.28	5.02
Choanal atresia, bilateral						0.16	0.25	0.34
Cleft palate without cleft lip						9.76	9.83	8.40
Cleft lip with or without cleft palate						10.23	10.51	10.37
Oesophageal atresia/stenosis with or without fistula						3.28	3.36	2.93
Small intestine atresia/stenosis						2.19	1.62	1.69
Anorectal atresia/stenosis						5.23	3.17	4.17
Undescended testis (36 weeks of gestation or later)						23.42	12.07	27.45
Hypospadias						31.22	30.55	27.00
Epispadias						0.62	0.25	0.17
Indeterminate sex						0.31	0.87	0.51
Renal agenesis						2.89	1.80	1.63
Cystic kidney						10.30	9.89	8.06
Bladder exstrophy						0.39	0.12	0.62
Polydactyly, preaxial						0.94	1.24	0.73
Total Limb reduction defects (include unspecified)						10.93	9.27	7.72
Transverse						5.00	4.67	4.23
Preaxial						1.72	1.31	1.30
Postaxial						0.78	0.25	0.17
Intercalary						1.41	1.93	0.90
Mixed						0.86	1.00	0.62
Unspecified						1.33	0.87	0.39
Diaphragmatic hernia						3.75	3.80	3.78
Omphalocele						3.43	4.29	4.06
Gastroschisis						4.84	7.15	5.07
Unspecified Omphalocele/Gastroschisis						0.47	0.56	0.28
Prune belly sequence						0.23	0.06	0.11
Trisomy 13						2.81	1.80	2.09
Trisomy 18						4.06	5.72	6.26
Down syndrome, all ages (include age unknown)						20.14	21.53	22.66
<20						10.35	5.88	9.87
20-24						8.28	6.97	10.82
25-29						11.66	10.13	8.78
30-34						18.44	15.15	20.37
35-39						54.57	59.08	54.70
40-44						150.06	172.63	148.12
45+						256.41	454.55	261.19
unknown						---	---	---

* data include less than 5 years

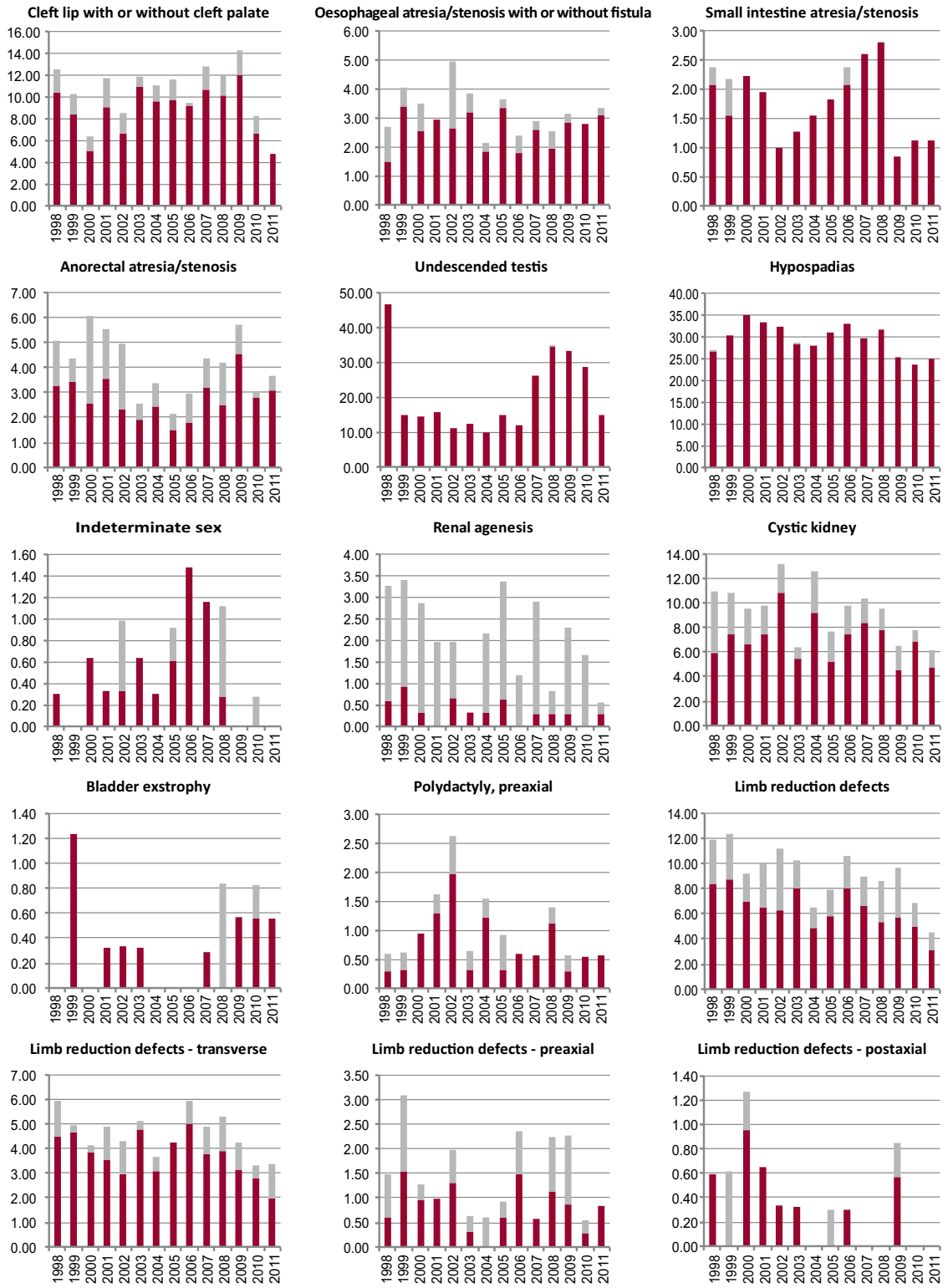
United Kingdom-Wales: CARIS

Time trends 1998-2011 (Birth prevalence rates per 10,000)



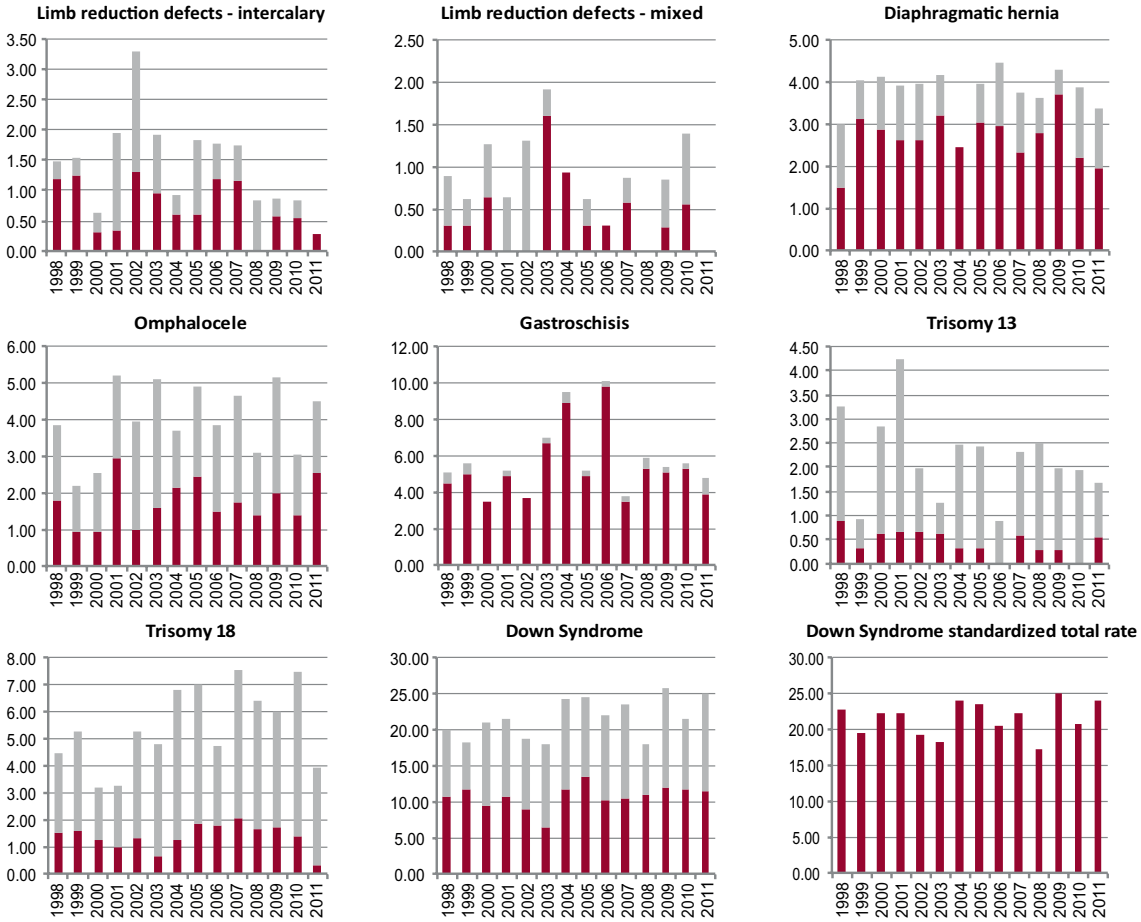
Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS



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 Program started in 1967 and was a founding member of the ICBDSR.

Size and coverage:
Between 1967 and 2011, the Program covered all births within a five-county area in metropolitan Atlanta, Georgia. The annual number of births in this area is approximately 50,000. Beginning in 2012, the area covered by the Program was reduced to 3 counties in metropolitan Atlanta, with approximately 35,000 live births. Stillbirths of at least 20 weeks gestation and elective terminations at any gestational age are included

Legislation and funding:
In 1994 the Georgia Department of Human Resources (now the Georgia Department of Public Health) added birth defects to the list of legally reportable conditions in Georgia. In 1997 the GDHR requested the staff of MACDP to act with them in the collection of public health surveillance data related to birth defects and stillbirths. The Program is funded by the Centers for Disease Control and Prevention

Sources of ascertainment:
Multiple sources, such as delivery units, pediatric departments, neonatal intensive care units, laboratories, prenatal diagnostic centers, tertiary care centers, and vital records 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 through interviews with mothers of reported malformed infants and often with mothers of infants without defects who participate in specific research projects.

Background information:
Number of live births and demographic information for the included counties are obtained from Georgia vital records.

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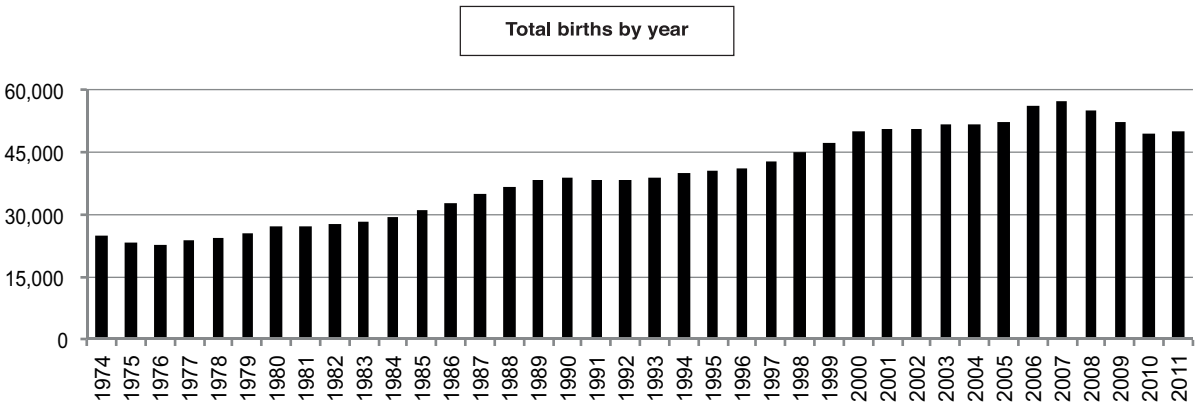
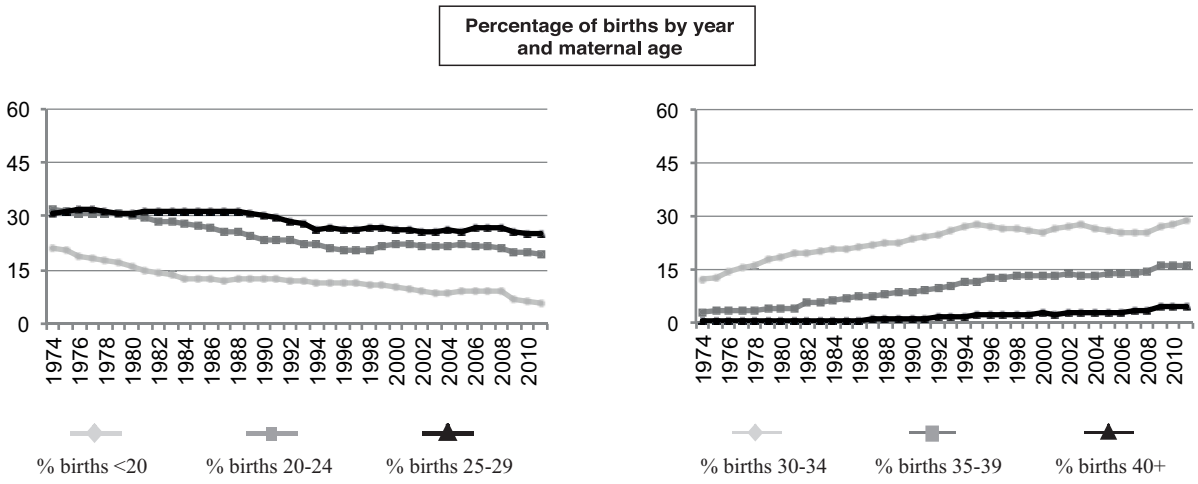
USA-Atlanta: MACDP





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	38	67.9	Cystic kidney	9	16.4
Spina bifida	23	29.5	Limb reduction defects	14	17.3
Encephalocele	8	40.0	Diaphragmatic hernia	8	16.0
Holoprosencephaly	9	29.0	Omphalocele	27	43.5
Hydrocephaly	16	13.6	Gastroschisis	7	12.5
Hypoplastic left heart syndrome	13	28.9	Trisomy 13	20	50.0
Cleft palate without cleft lip	5	6.3	Trisomy 18	59	55.1
Cleft lip with or without cleft palate	23	16.8	Down syndrome	93	28.6
Renal agenesis	14	14.1			

Total ToPs with births defects = 260 (Ratio ToPs/Births: 1.72 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Atlanta: MACDP, 2011

Live births (LB)	49,220
Stillbirths (SB)	479
Total births	49,699
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	10	3.42
Spina bifida	11	4	9	4.83
Encephalocele(*)	4	0	2	1.21
Microcephaly	nr	nr	nr	nr
Holoprosencephaly	8	3	5	3.22
Hydrocephaly	nr	nr	nr	nr
Anophthalmos	1	0	1	0.40
Microphthalmos	8	0	0	1.61
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	3	0	1	0.80
Microtia	10	0	0	2.01
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	13	0	1	2.82
Tetralogy of Fallot	20	3	3	5.23
Hypoplastic left heart syndrome	9	0	7	3.22
Coarctation of aorta	31	1	5	7.44
Choanal atresia, bilateral (**)	7	0	0	1.41
Cleft palate without cleft lip	15	2	1	3.62
Cleft lip with or without cleft palate	32	1	6	7.85
Oesophageal atresia/stenosis with or without fistula	12	0	0	2.41
Small intestine atresia/stenosis	22	0	0	4.43
Anorectal atresia/stenosis	24	2	0	5.23
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	200	0	1	40.44
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis(***)	39	1	6	9.26
Cystic kidney	nr	nr	nr	nr
Bladder exstrophy	0	0	2	0.40
Polydactyly, preaxial	nr	nr	nr	nr
Total Limb reduction defects (include unspecified)	20	3	5	5.63
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	7	2	3	2.41
Omphalocele	6	4	13	4.63
Gastroschisis	18	2	2	4.43
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	5	6	5	3.22
Trisomy 18	7	6	19	6.44
Down syndrome, all ages (include age unknown)	72	4	26	20.52
<20	3	0	0	10.44
20-24	5	0	1	6.22
25-29	13	0	1	11.17
30-34	14	2	4	14.00
35-39	20	1	12	41.38
40-44	14	1	8	105.60
45+	3	0	0	149.25
unknown	0	0	0	---

nr = data not reported or not available
Pregnancies diagnosed prenatally with unknown outocome that did not deliver in a hospital are assumed to have been electively terminated
(*) Cases with both anencephaly and encephalocele are included only in the category for anencephaly
(**) Information on laterality for choanal atresia was not available. All cases are included
(***) Renal agenesis includes bilateral renal dysplasia and hypoplasia.

USA-Atlanta: MACDP, Previous years rates 1974-2011

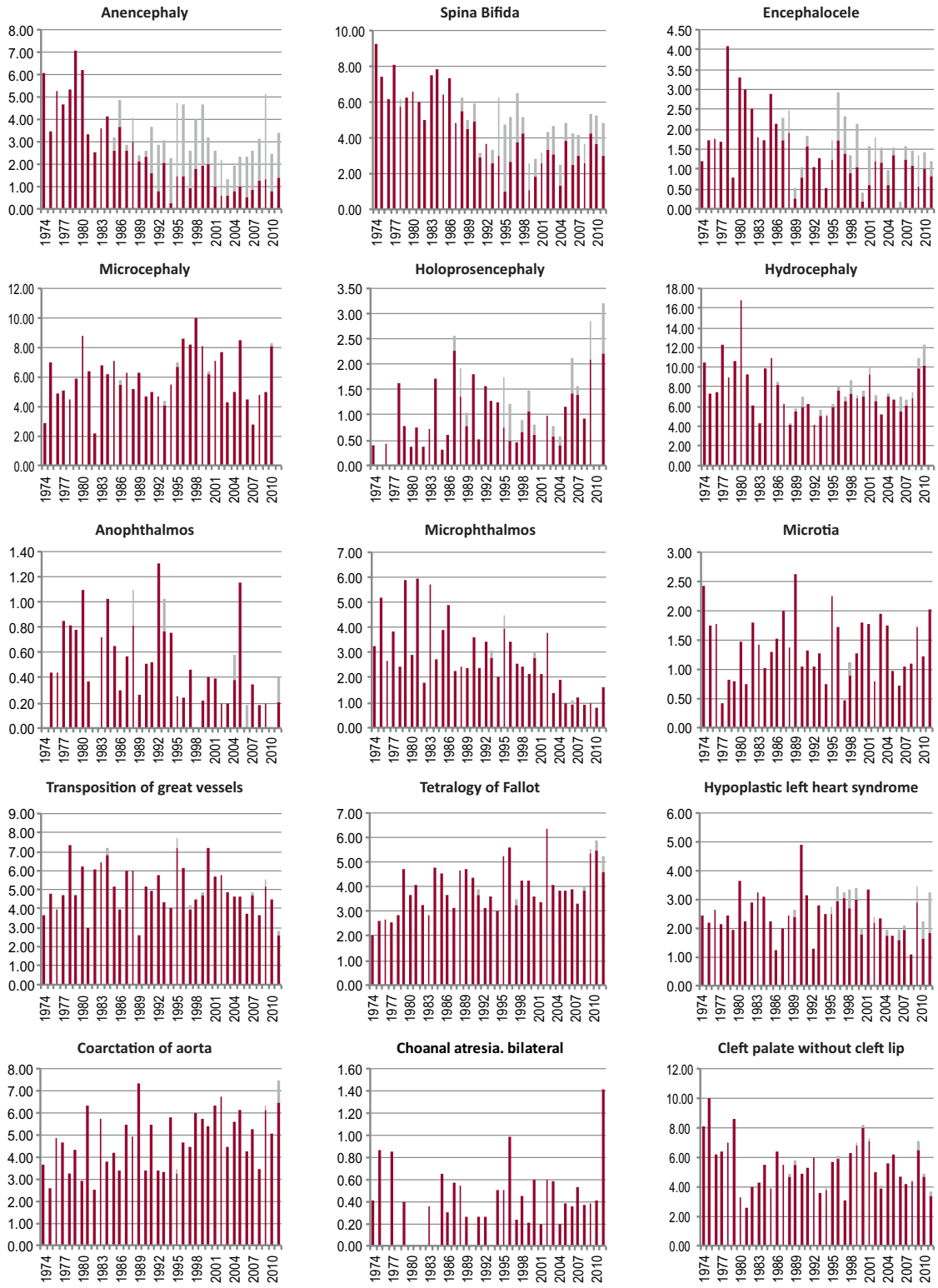
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001	2002-2006	2007-2011
Total births	**70,480**	**127,639**	**148,828**	**186,757**	**198,299**	**235,616**	**262,250**	**263,574**
Anencephaly	4.97	5.33	3.70	3.11	3.53	3.40	2.02	3.34
Spina bifida	7.66	6.58	6.85	5.03	4.64	3.95	4.12	4.63
Encephalocele	1.56	2.59	2.22	1.61	1.51	1.53	1.18	1.40
Microcephaly	4.82	6.19	5.64	5.46	6.05	7.89	5.95	5.10*
Holoprosencephaly	0.28	0.71	0.74	1.55	1.41	0.72	1.14	2.10*
Hydrocephaly	8.51	11.67	8.06	5.94	5.90	8.15	6.67	9.21*
Anophthalmos	0.28	0.78	0.54	0.59	0.71	0.30	0.46	0.23
Microphthalmos	3.69	4.23	3.83	2.62	3.28	2.46	1.79	1.10
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00*
Anotia	0.43	0.00	0.20	0.16	0.20	0.21	0.19	0.34
Microtia	1.99	0.86	1.41	1.66	1.41	1.32	1.22	1.40
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00*
Transposition of great vessels	4.11	5.17	5.71	4.93	5.60	5.35	4.69	4.29
Tetralogy of Fallot	2.41	3.60	3.83	4.18	4.14	3.78	4.39	4.74
Hypoplastic left heart syndrome	2.41	2.51	2.49	3.05	2.57	3.06	2.06	2.39
Coarctation of aorta	3.69	4.31	3.90	5.30	4.14	5.60	5.41	5.46
Choanal atresia, bilateral	0.43	0.24	0.27	0.32	0.45	0.34	0.42	0.61
Cleft palate without cleft lip	8.09	5.48	4.84	5.25	5.09	6.45	5.07	4.82
Cleft lip with or without cleft palate	12.49	10.89	10.48	9.48	9.48	8.45	9.27	9.11
Oesophageal atresia/stenosis with or without fistula	2.70	2.66	2.28	1.93	2.32	2.33	1.79	2.35
Small intestine atresia/stenosis	1.70	1.41	1.48	1.98	1.66	1.95	1.91	2.80*
Anorectal atresia/stenosis	4.97	4.15	3.90	3.91	3.33	3.82	2.82	4.34*
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	16.34	15.44	7.48*
Hypospadias	1.28	0.94	3.56	4.50	5.35	9.17	7.13	17.60
Epispadias	0.85	1.02	0.87	0.64	0.50	0.30	0.65	0.33*
Indeterminate sex	1.28	3.06	1.14	1.12	1.21	1.49	1.53	1.64*
Renal agenesis	1.56	2.19	1.68	1.29	1.56	0.85	0.99	4.10
Cystic kidney	2.84	2.04	3.90	3.91	5.70	6.24	6.14	6.87*
Bladder exstrophy	0.57	0.47	0.07	0.21	0.30	0.13	0.11	0.23*
Polydactyly, preaxial	1.28	2.35	1.88	3.27	3.08	2.29	2.25	2.25*
Total Limb reduction defects (include unspecified)	6.53	5.17	4.57	4.39	6.25	6.32	4.08	4.89
Transverse	4.40	2.98	3.36	2.62	4.14	3.23	2.21	2.80*
Preaxial	1.14	1.02	0.47	0.80	1.01	1.36	0.69	0.61*
Postaxial	0.14	0.31	0.13	0.32	0.30	0.25	0.31	0.18*
Intercalary	0.28	0.55	0.20	0.32	0.25	0.21	0.19	0.49*
Mixed	0.00	0.16	0.34	0.21	0.35	0.98	0.53	0.67*
Unspecified	0.57	0.16	0.07	0.11	0.20	0.30	0.11	0.24*
Diaphragmatic hernia	3.26	1.96	2.35	3.00	2.12	2.42	2.94	2.96
Omphalocele	4.26	3.60	3.49	2.46	2.47	2.55	1.72	3.30
Gastroschisis	0.85	2.04	2.08	2.78	2.22	2.25	3.36	4.40
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.05	0.00	0.00	0.00	0.00*
Prune belly sequence	0.57	0.86	0.47	0.32	0.20	0.51	0.38	0.49*
Trisomy 13	1.14	1.02	1.48	1.39	1.46	1.95	1.87	1.93
Trisomy 18	0.57	1.18	1.95	2.14	2.98	4.71	4.35	5.46
Down syndrome, all ages (include age unknown)	9.51	10.03	9.94	10.98	15.63	17.15	17.12	19.27
<20	nr	10.62*	5.62	7.36	7.76	7.76	8.07	9.56
20-24	nr	6.78*	7.47	7.85	7.84	7.90	6.76	7.02
25-29	nr	11.33*	6.42	6.97	8.75	7.53	7.15	9.50
30-34	nr	17.63*	14.71	13.33	13.12	13.50	14.30	14.79
35-39	nr	31.52*	17.91	23.38	39.40	48.35	41.21	41.40
40-44	nr	106.38*	67.34	49.02	116.89	108.46	127.35	98.85
45+	nr	0.00*	0.00	0.00	413.22	241.94	103.36	144.17
unknown	---	---	---	---	---	---	---	---

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

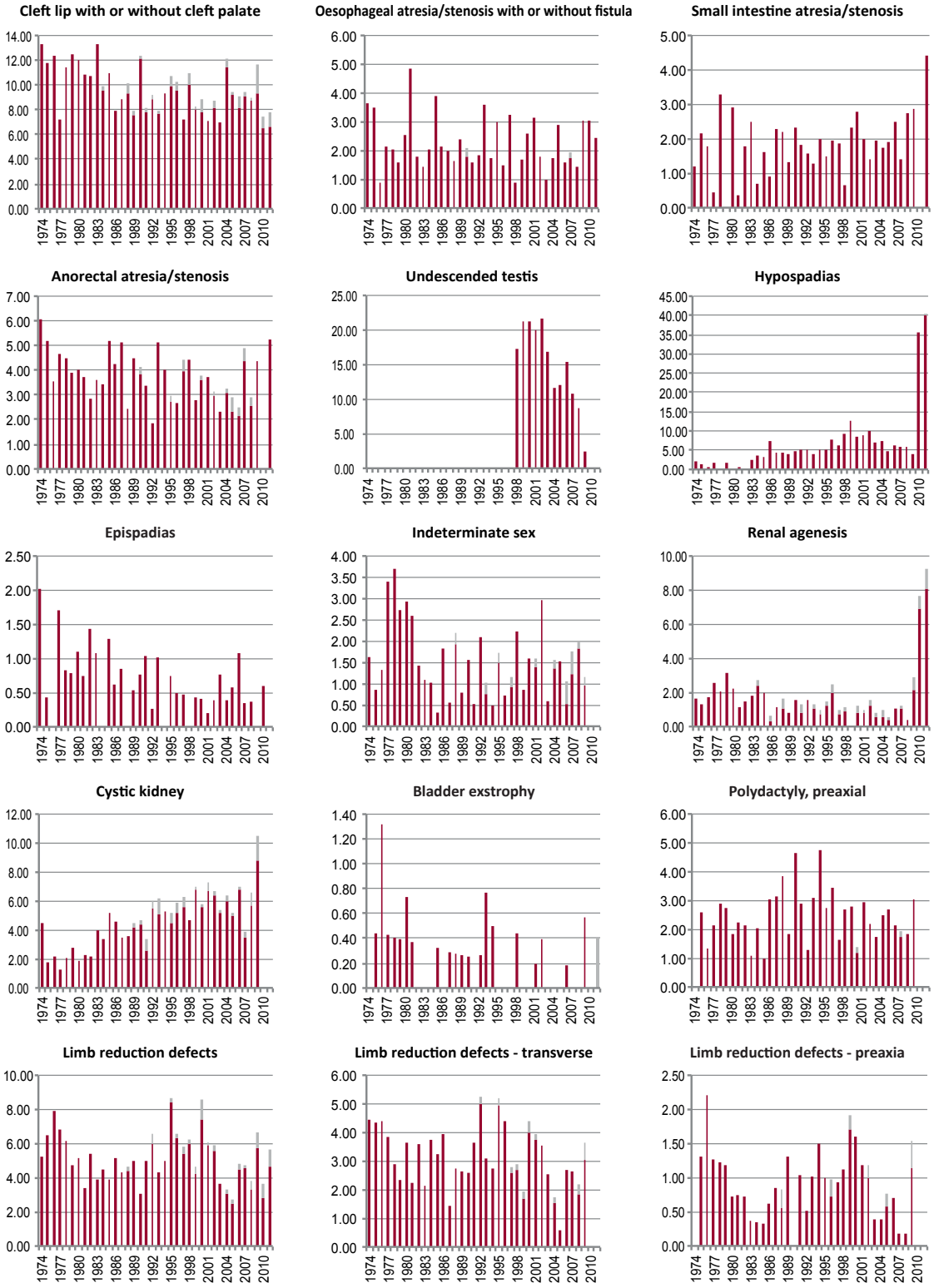
USA-Atlanta: MACDP

Time trends 1974-2011 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

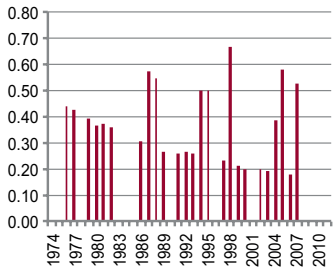
USA-Atlanta: MACDP



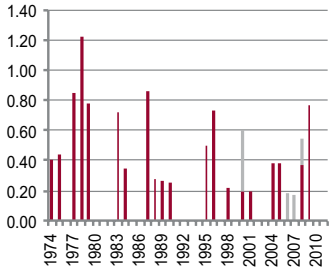
Note: L+S rates, ToP rates

USA-Atlanta: MACDP

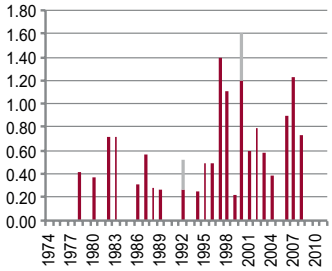
Limb reduction defects - postaxial



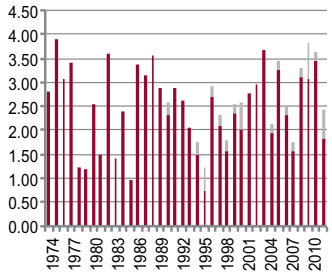
Limb reduction defects - intercalary



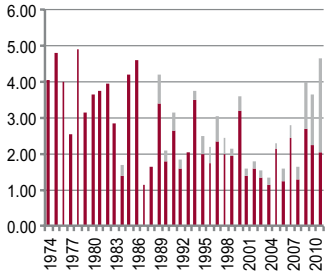
Limb reduction defects - mixed



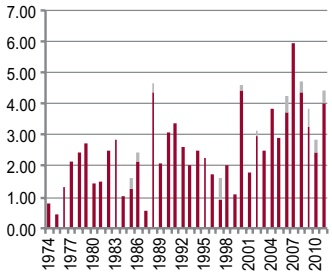
Diaphragmatic hernia



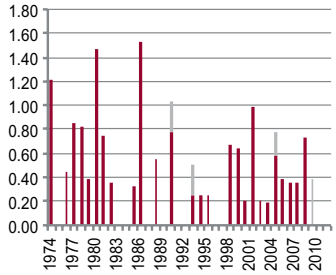
Omphalocele



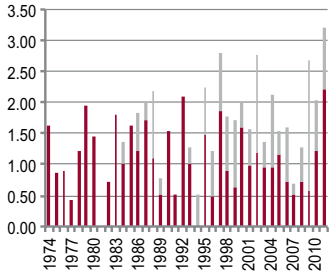
Gastroschisis



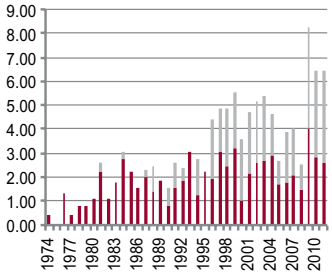
Prune belly sequence



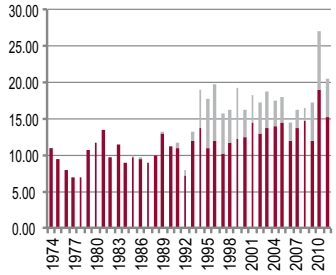
Trisomy 13



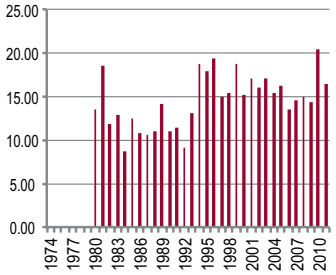
Trisomy 18



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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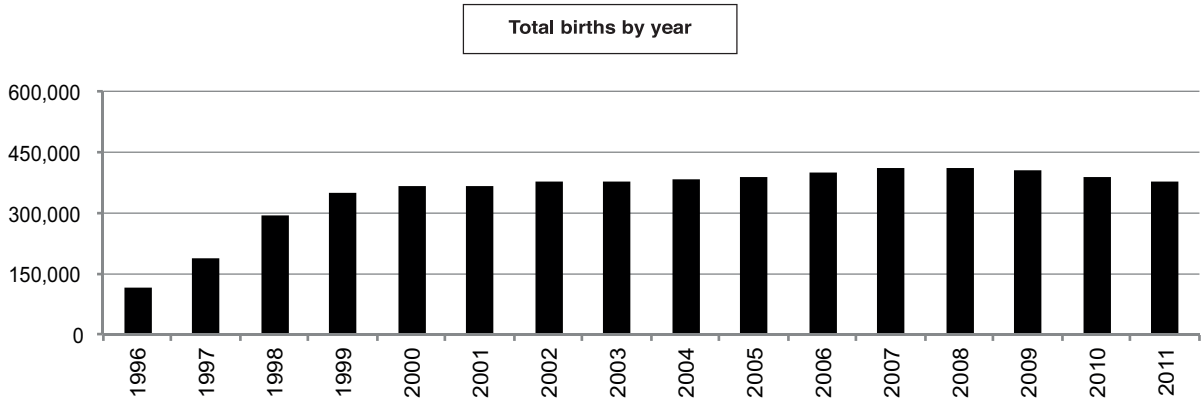
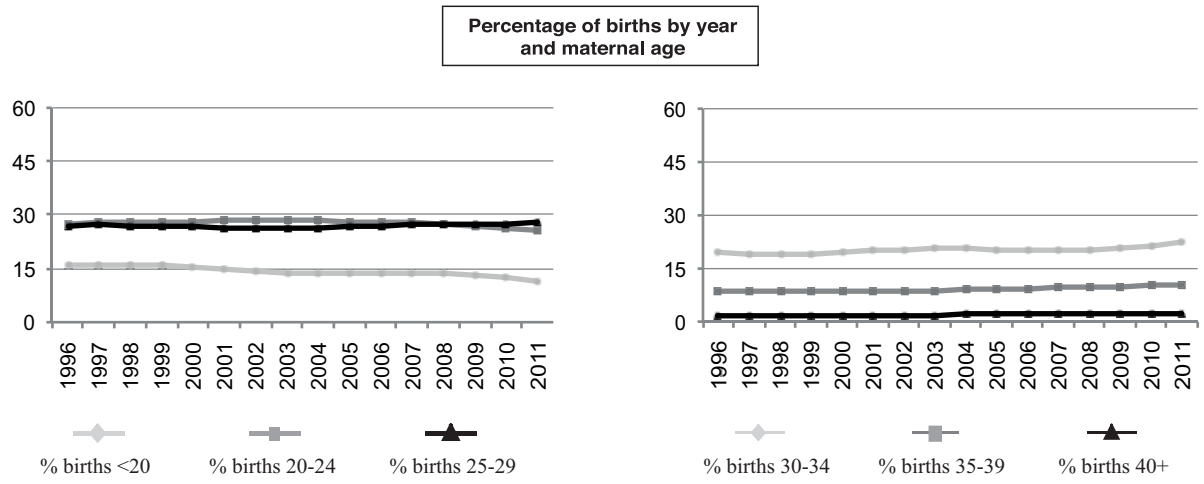
USA-Texas: BDES





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	110	32.8	Cystic kidney	8	1.1
Spina bifida	19	4.0	Limb reduction defects	23	3.2
Encephalocele	13	10.6	Diaphragmatic hernia	3	0.9
Holoprosencephaly	8	6.7	Omphalocele	18	7.6
Hydrocephaly	9	1.0	Gastroschisis	9	1.3
Hypoplastic left heart syndrome	3	1.1	Trisomy 13	25	16.1
Cleft palate without cleft lip	2	0.3	Trisomy 18	68	21.1
Cleft lip with or without cleft palate	39	3.2	Down syndrome	40	2.4
Renal agenesis	19	8.3			

Total ToPs with births defects = 376 (Ratio ToPs/Births: 0.32 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Texas: BDES, 2011

Live births (LB)	377,336
Stillbirths (SB)	2,087
Total births	379,423
Number of terminations of pregnancy (ToP) for birth defects	167

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	33	30	38	2.66
Spina bifida	153	7	4	4.32
Encephalocele	36	1	5	1.11
Microcephaly	540	1	0	14.26
Holoprosencephaly	37	4	4	1.19
Hydrocephaly	293	4	2	7.88
Anophthalmos	17	0	2	0.50
Microphthalmos	108	3	1	2.95
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	10	1	0	0.29
Microtia	126	0	0	3.32
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	189	2	2	5.09
Tetralogy of Fallot	162	1	0	4.30
Hypoplastic left heart syndrome	82	3	0	2.24
Coarctation of aorta	211	3	0	5.64
Choanal atresia, bilateral	53	0	0	1.40
Cleft palate without cleft lip	190	11	0	5.30
Cleft lip with or without cleft palate	418	20	12	11.86
Oesophageal atresia/stenosis with or without fistula	87	4	0	2.40
Small intestine atresia/stenosis	67	0	0	1.77
Anorectal atresia/stenosis	176	15	5	5.17
Undescended testis (36 weeks of gestation or later)	560	2	0	14.81
Hypospadias	659	2	0	17.42
Epispadias	36	0	0	0.95
Indeterminate sex	11	27	8	1.21
Renal agenesis	57	8	5	1.84
Cystic kidney	231	3	1	6.19
Bladder exstrophy	6	0	0	0.16
Polydactyly, preaxial	159	1	0	4.22
Total Limb reduction defects (include unspecified)	220	17	8	6.46
Transverse	100	11	4	3.03
Preaxial	62	2	0	1.69
Postaxial	7	0	0	0.18
Intercalary	6	0	1	0.18
Mixed	33	2	3	1.00
Unspecified	12	2	0	0.37
Diaphragmatic hernia	100	1	0	2.66
Omphalocele	48	12	9	1.82
Gastroschisis	202	13	2	5.72
Unspecified Omphalocele/Gastroschisis	13	7	3	0.61
Prune belly sequence	6	1	0	0.18
Trisomy 13	28	7	8	1.13
Trisomy 18	60	25	24	2.87
Down syndrome, all ages (include age unknown)	519	25	13	14.68
<20	24	2	0	6.00
20-24	73	1	1	7.73
25-29	73	4	0	7.30
30-34	98	6	4	12.74
35-39	150	6	5	41.21
40-44	87	4	3	107.40
45+	14	2	0	318.73
unknown	0	0	0	---

(*) Only definite diagnosed cases are reported.

USA-Texas: BDES, Previous years rates 1996 - 2011

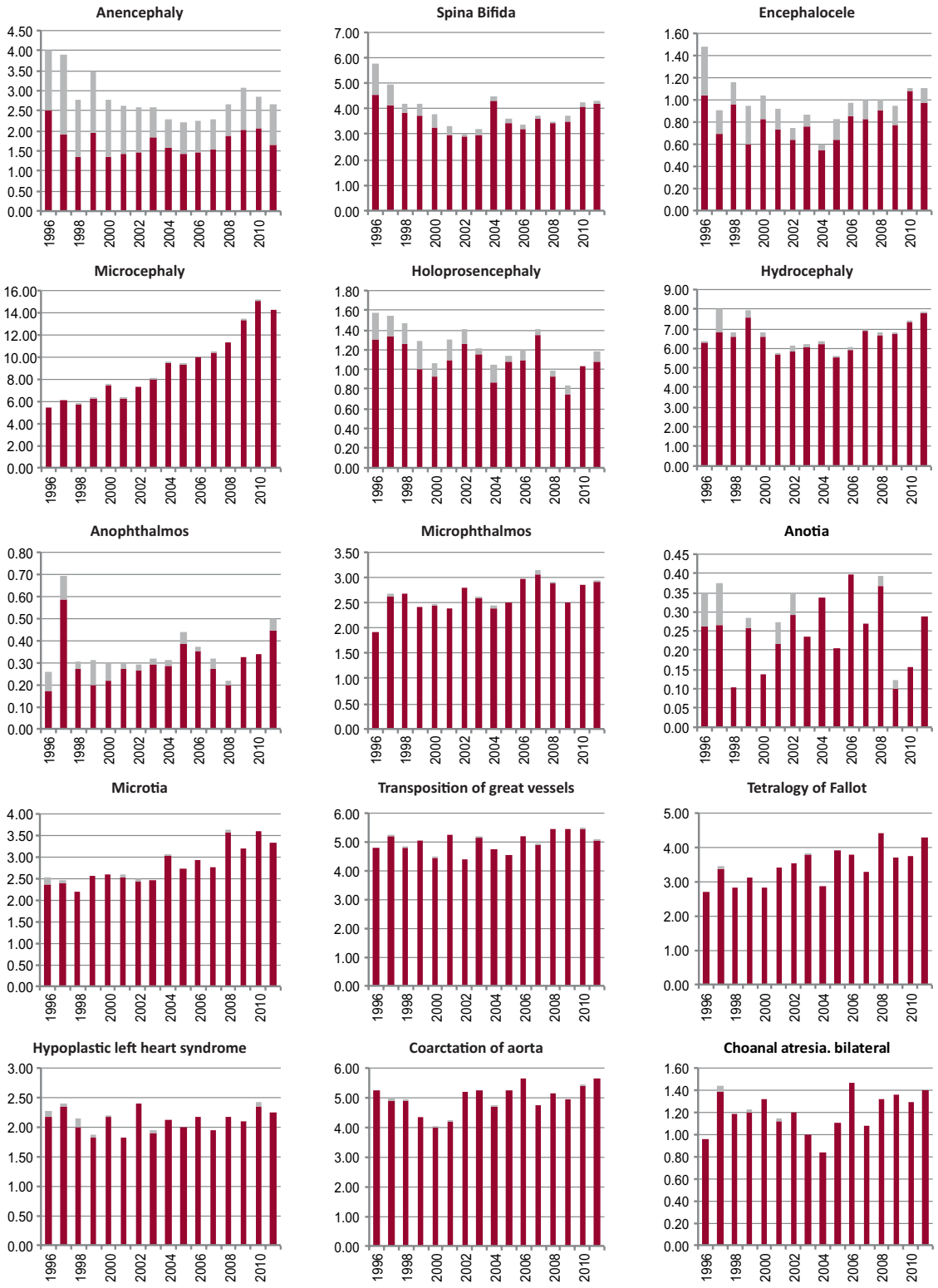
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996*	1997-2001	2002-2006	2007-2011
Total births					**114,765**	**1,565,369**	**1,927,544**	**1,988,714**
Anencephaly					4.01	3.03	2.39	2.70
Spina bifida					5.75	3.99	3.55	3.91
Encephalocele					1.48	1.00	0.80	1.03
Microcephaly					5.49	6.44	8.87	12.82
Holoprosencephaly					1.57	1.30	1.20	1.09
Hydrocephaly					6.36	6.96	6.05	7.16
Anophthalmos					0.26	0.35	0.35	0.34
Microphthalmos					1.92	2.51	2.68	2.88
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00	0.00
Anotia					0.35	0.22	0.31	0.25
Microtia					2.53	2.49	2.73	3.30
Unspecified Anotia/Microtia					0.00	0.00	0.00	0.00
Transposition of great vessels					4.79	4.94	4.81	5.28
Tetralogy of Fallot					2.70	3.12	3.58	3.88
Hypoplastic left heart syndrome					2.27	2.05	2.12	2.18
Coarctation of aorta					5.23	4.43	5.21	5.17
Choanal atresia, bilateral					0.96	1.25	1.13	1.29
Cleft palate without cleft lip					5.58	5.85	5.30	5.86
Cleft lip with or without cleft palate					10.19	10.86	10.76	10.43
Oesophageal atresia/stenosis with or without fistula					2.09	2.12	2.02	2.12
Small intestine atresia/stenosis					1.66	1.75	1.69	2.00
Anorectal atresia/stenosis					4.01	4.50	5.06	4.84
Undescended testis (36 weeks of gestation or later)					5.66	8.37	10.32	13.70
Hypospadias					15.77	18.19	15.82	16.59
Epispadias					0.70	0.68	0.71	0.95
Indeterminate sex					1.48	1.47	0.79	0.93
Renal agenesis					1.66	2.11	1.89	1.99
Cystic kidney					4.71	4.39	5.17	6.01
Bladder exstrophy					0.17	0.20	0.22	0.18
Polydactyly, preaxial					2.18	2.97	3.51	4.00
Total Limb reduction defects (include unspecified)					5.49	5.51	5.30	5.97
Transverse					2.35	2.66	2.81	3.02
Preaxial					1.39	1.12	1.10	1.36
Postaxial					0.35	0.24	0.23	0.21
Intercalary					0.17	0.10	0.13	0.21
Mixed					1.13	1.20	0.81	0.93
Unspecified					0.09	0.20	0.21	0.26
Diaphragmatic hernia					2.61	2.63	2.72	2.91
Omphalocele					1.83	2.33	2.03	2.00
Gastroschisis					3.22	3.90	4.66	6.14
Unspecified Omphalocele/Gastroschisis					0.96	0.63	0.60	0.60
Prune belly sequence					0.44	0.26	0.31	0.26
Trisomy 13					0.96	1.24	1.08	1.26
Trisomy 18					3.14	2.27	2.41	2.73
Down syndrome, all ages (include age unknown)					11.94	12.54	12.79	14.01
<20					6.57	7.34	7.50	6.96
20-24					5.35	7.01	6.39	7.25
25-29					6.14	7.38	7.07	7.71
30-34					12.56	12.20	12.50	13.01
35-39					38.39	36.15	36.11	37.79
40-44					138.01	118.50	112.97	114.35
45+					0.00	167.60	187.01	208.50
unknown					---	---	---	---

* data include less than 5 years

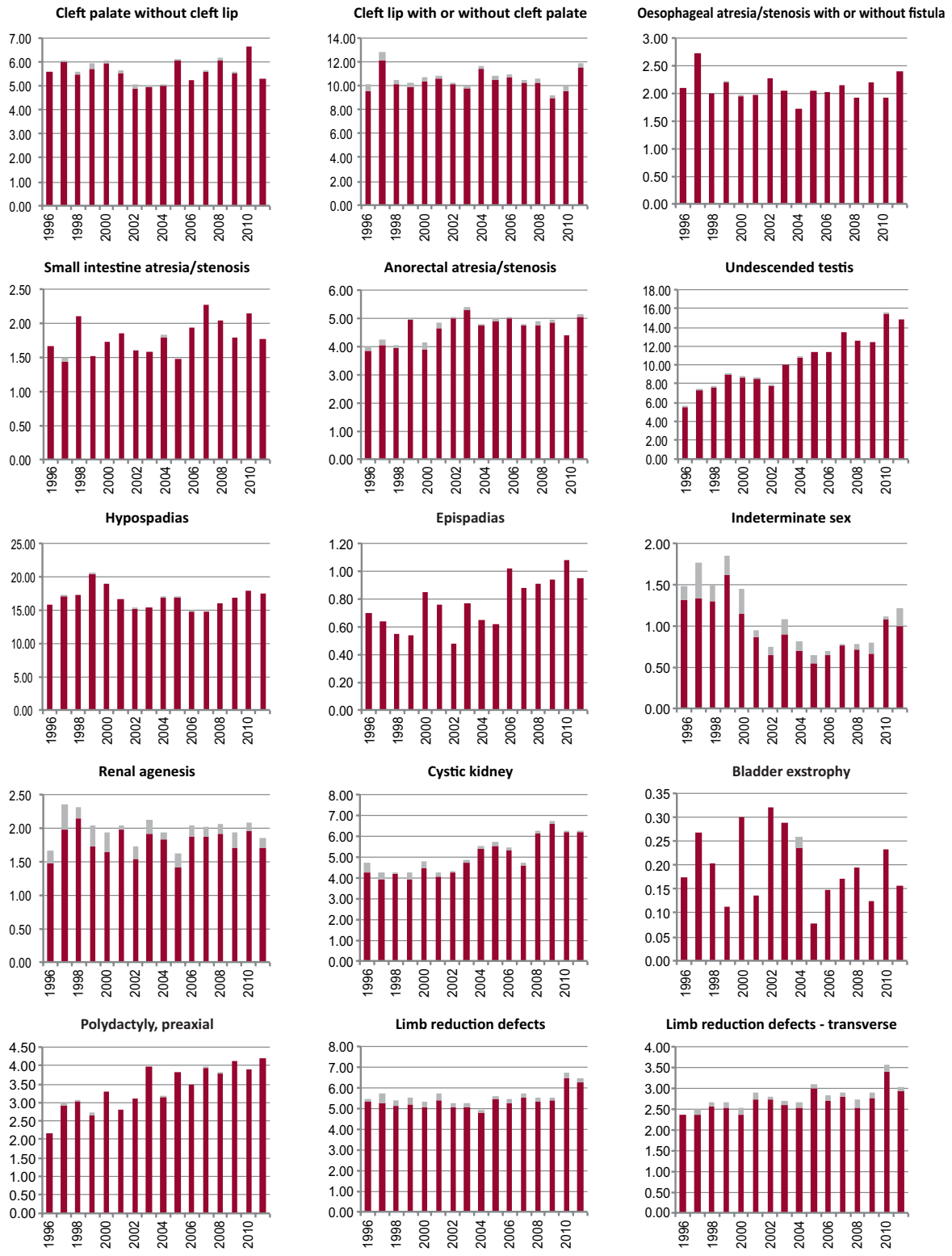
USA-Texas: BDES

Time trends 1996-2011 (Birth prevalence rates per 10,000)



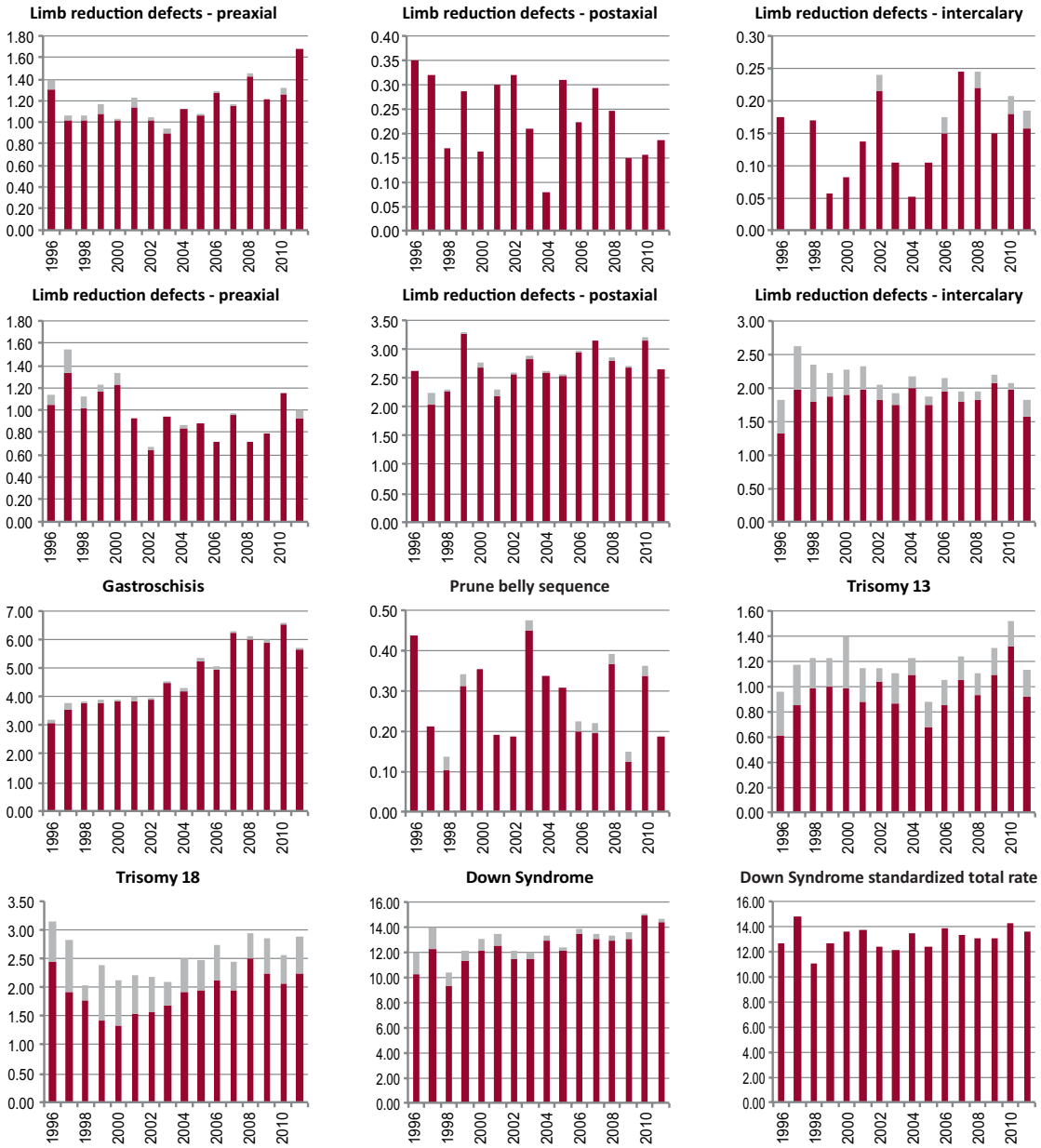
Note: L+S rates, ToP rates

USA-Texas: BDES



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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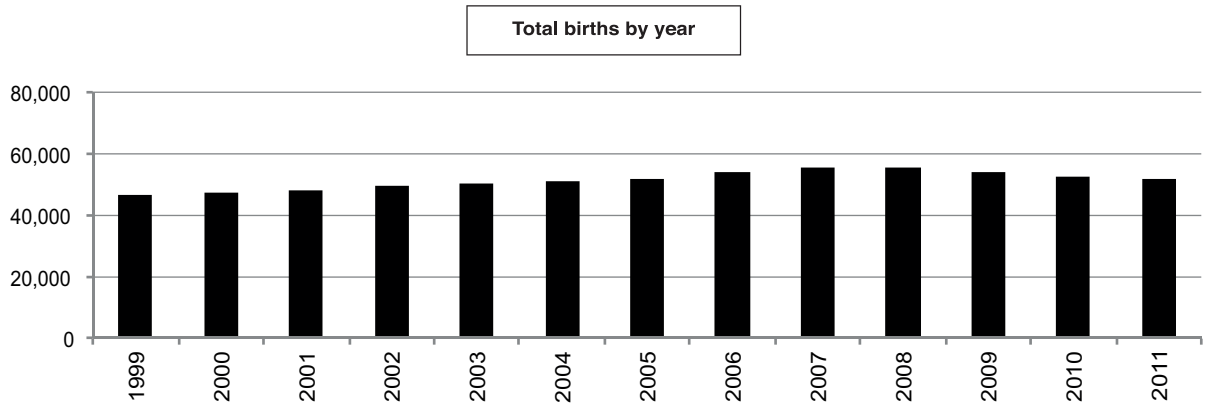
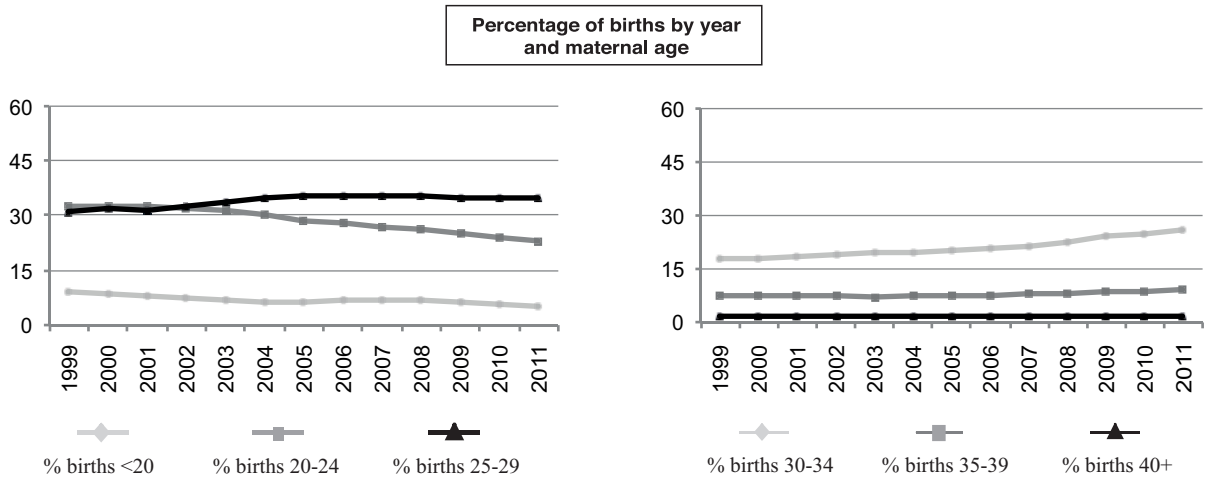
USA-Utah: UBDN





Terminations of pregnancy (ToPs) in selected malformations (2009-2011)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	27	60.0	Cystic kidney	10	11.6
Spina bifida	4	9.1	Limb reduction defects	3	3.0
Encephalocele	3	25.0	Diaphragmatic hernia	1	2.1
Holoprosencephaly	6	26.1	Omphalocele	9	17.6
Hydrocephaly	0	0.0	Gastroschisis	2	3.3
Hypoplastic left heart syndrome	5	9.8	Trisomy 13	10	35.7
Cleft palate without cleft lip	0	0.0	Trisomy 18	12	22.6
Cleft lip with or without cleft palate	10	4.5	Down syndrome	29	12.1
Renal agenesis	8	14.3			

Total ToPs with births defects = 120 (Ratio ToPs/Births: 0.76 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Utah: UBDN, 2011

Live births (LB)	51,144
Stillbirths (SB)	278
Total births	51,422
Number of terminations of pregnancy (ToP) for birth defects	39

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	2	8	2.72
Spina bifida	14	0	0	2.72
Encephalocele	2	0	1	0.58
Microcephaly	9	0	0	1.75
Holoprosencephaly	3	1	2	1.17
Hydrocephaly	4	0	0	0.78
Anophthalmos	2	0	0	0.39
Microphthalmos	8	0	0	1.56
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.39
Microtia	27	0	0	5.25
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	13	1	0	2.72
Tetralogy of Fallot	15	0	0	2.92
Hypoplastic left heart syndrome	11	0	4	2.92
Coarctation of aorta	50	3	3	10.89
Choanal atresia, bilateral	6	0	0	1.17
Cleft palate without cleft lip	22	0	0	4.28
Cleft lip with or without cleft palate	64	6	2	14.00
Oesophageal atresia/stenosis with or without fistula	9	0	0	1.75
Small intestine atresia/stenosis	7	0	0	1.36
Anorectal atresia/stenosis	11	0	3	2.72
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	50	0	0	9.72
Epispadias	1	0	0	0.19
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	18	1	5	4.67
Cystic kidney	31	0	2	6.42
Bladder exstrophy	1	0	0	0.19
Polydactyly, preaxial	nr	nr	nr	nr
Total Limb reduction defects (include unspecified)	36	2	1	7.58
Transverse	20	2	0	4.28
Preaxial	8	0	1	1.75
Postaxial	1	0	0	0.19
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	2	0	0	0.39
Diaphragmatic hernia	16	0	0	3.11
Omphalocele	10	1	2	2.53
Gastroschisis	13	0	1	2.72
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	4	2	0	1.17
Trisomy 13	3	2	3	1.56
Trisomy 18	9	4	6	3.69
Down syndrome, all ages (include age unknown)	72	5	8	16.53
<20	0	0	0	0.00
20-24	8	1	0	7.63
25-29	16	1	0	9.53
30-34	15	1	1	12.78
35-39	23	1	4	59.05
40-44	8	1	2	132.05
45+	2	0	1	714.29
unknown	0	0	0	---

nr = data not reported or not available

USA-Utah: UBDN, Previous years rates 1999 - 2011

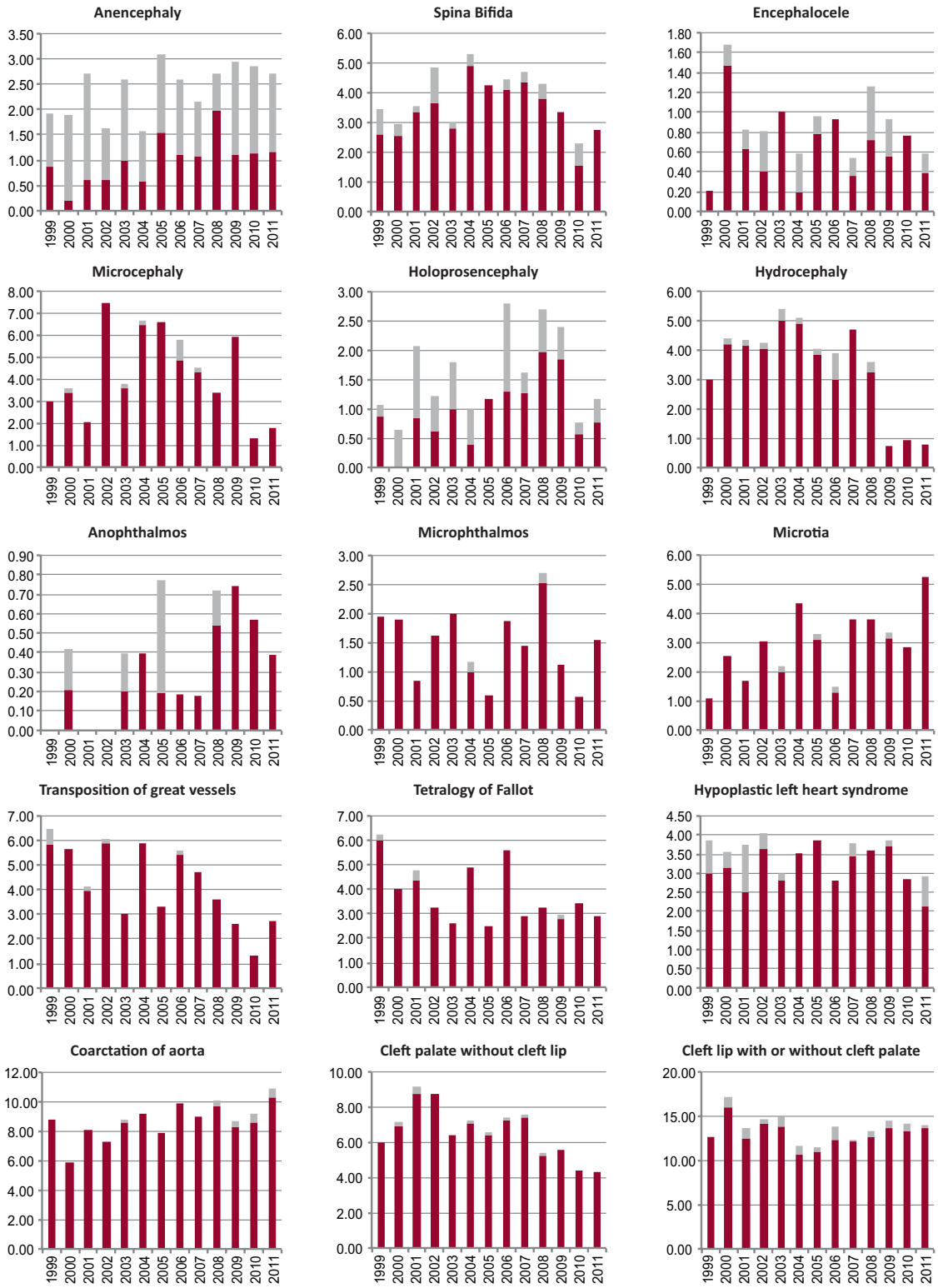
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1976	1977-1981	1982-1986	1987-1991	1992-1996	1997-2001*	2002-2006	2007-2011
Total births						**142,188**	**255,878**	**268,952**
Anencephaly						2.18	2.31	2.68
Spina bifida						3.31	4.38	3.50
Encephalocele						0.91	0.86	0.82
Microcephaly						2.88	6.06	3.42
Holoprosencephaly						1.27	1.60	1.75
Hydrocephaly						3.94	4.53	2.19
Anophthalmos						0.14	0.35	0.52
Microphthalmos						1.55	1.45	1.49
Unspecified Anophthalmos/Microphthalmos						0.00	0.00	0.00
Anotia						0.21	0.16	0.11
Microtia						1.76	2.85	3.79
Unspecified Anotia/Microtia						0.00	0.00	0.00
Transposition of great vessels						5.42	4.77	3.01
Tetralogy of Fallot						4.99	3.79	3.09
Hypoplastic left heart syndrome						3.73	3.44	3.42
Coarctation of aorta						7.60	8.64	9.56
Choanal atresia, bilateral						0.07	0.31	0.89
Cleft palate without cleft lip						7.45	7.27	5.47
Cleft lip with or without cleft palate						14.56	13.25	13.61
Oesophageal atresia/stenosis with or without fistula						2.74	2.46	2.75
Small intestine atresia/stenosis						1.27	1.41	1.41
Anorectal atresia/stenosis						3.09	3.52	3.23
Undescended testis (36 weeks of gestation or later)						nr	nr	nr
Hypospadias						4.29	6.96	9.52
Epispadias						0.28	0.12	0.11
Indeterminate sex						nr	nr	nr
Renal agenesis						3.59	3.67	3.27
Cystic kidney						5.20	5.39	4.80
Bladder exstrophy						0.28	0.12	0.26
Polydactyly, preaxial						nr	nr	nr
Total Limb reduction defects (include unspecified)						5.84	6.41	6.43
Transverse						3.31	3.20	3.31
Preaxial						1.48	1.56	1.45
Postaxial						0.07	0.12	0.33
Intercalary						0.07	0.12	0.26
Mixed						0.70	1.02	0.52
Unspecified						0.14	0.16	0.37
Diaphragmatic hernia						3.38	3.36	3.27
Omphalocele						2.60	2.74	2.94
Gastroschisis						4.22	5.20	4.61
Unspecified Omphalocele/Gastroschisis						0.00	0.00	0.00
Prune belly sequence						0.14	0.16	0.56
Trisomy 13						1.48	1.91	1.75
Trisomy 18						3.38	3.56	3.38
Down syndrome, all ages (include age unknown)						15.12	15.32	14.54
<20						8.03	11.73	6.62
20-24						8.18	9.23	6.70
25-29						8.04	9.05	7.97
30-34						12.37	14.03	13.71
35-39						60.45	46.57	41.87
40-44						143.21	142.97	173.61
45+						413.79	406.09	326.09
unknown						---	---	---

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

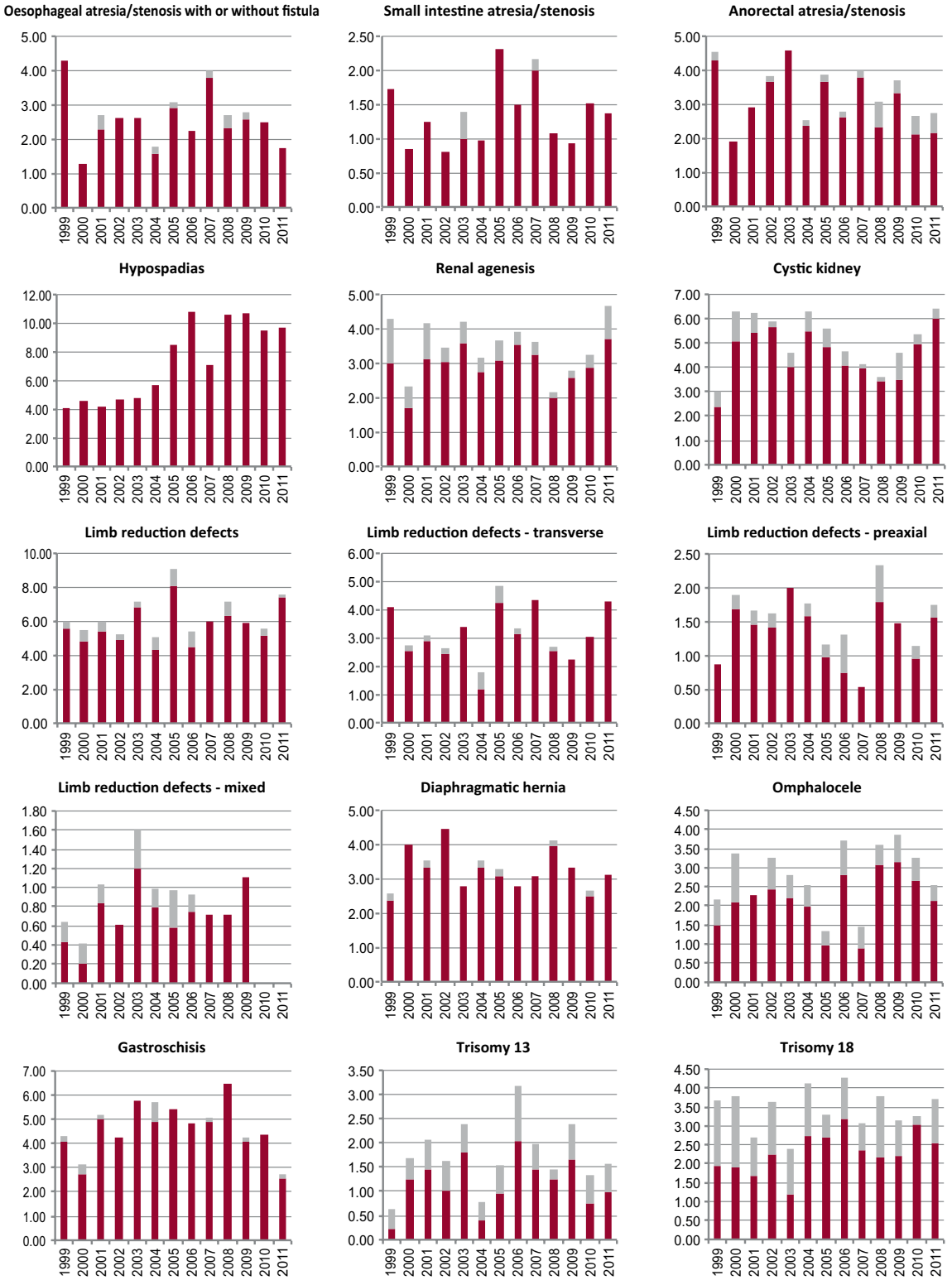
USA-Utah: UBDN

Time trends 1999-2011 (Birth prevalence rates per 10,000)



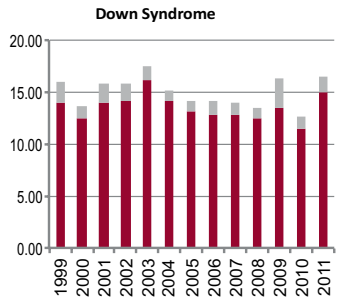
Note: L+S rates, ToP rates

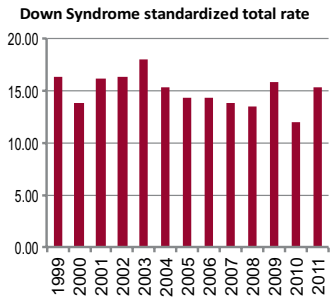
USA-Utah: UBDN



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

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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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.

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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.

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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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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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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.

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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-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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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.

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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

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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.

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