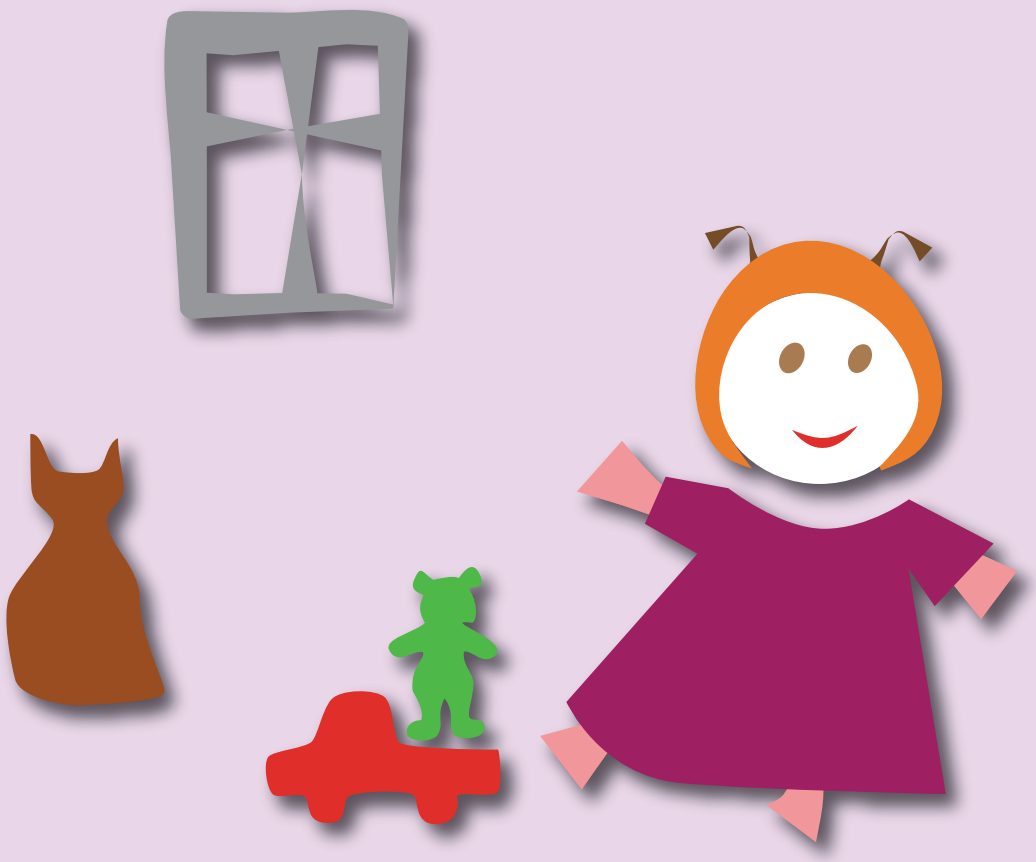
ANNUAL REPORT 2011

with data for **2009**

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH



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INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH (ICBDSR)

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

Annual Report

2011

with data for 2009

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ISSN 0743-5703
The International Centre on Birth Defects – ICBDSR Centre
acknowledges the financial support from the Centers for Diseases Control and Prevention, Atlanta, USA
(CDC Grant no. 1U50/DD000524-03)

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH
ANNUAL REPORT 2011 (WITH DATA FOR 2009)

Contents

Collaborative Research Projects

Multiple Congenital Anomalies (MCA), 2009

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

Introduction

For the year 2009, we received data from 7 programmes, for a total of 2,193 reported cases, among 424,889 births (Table 1). Of these, 567 were reported as syndromes and 872 had at least two major, unrelated congenital anomalies, which is our current case definition of multiple congenital anomaly (MCA). Coding, review of the cases, and comments were done by Monica Rittler, statistical analyses and report writing by Jorge López-Camelo.

Main findings and comments

This year, among the 47 defect groups, 34 were associated with an O/E ratio greater than 1. Five 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 4 two-defect combinations (Table 3), while no three-defect combination was significantly increased.
For all comparisons, the data reported from 1992 through 2006, over 5,504,969 births were used as baseline.

Table 1: Cases of multiple congenital anomalies, by programme and number of defects (2009).

PROGRAMME	Births	Total cases Reported	Known etiology (syndromes)	< 2 major unrelated defects	2 Or + unrelatedr defects	Rate
Canada-British Columbia	44,580	272	40	153	79	17.72
Finland	60,635	345	179	39	127	20.94
Israel	42,875	45	3	2	40	9.33
Japan	92,256	709	215	303	191	20.70
Mexico	13,542	40	1	2	37	27.32
South America ECLAMC	128,118	822	129	380	313	24.43
Usa Atlanta	52,346	115	5	11	99	18.91
UK Wales	35,117	117	35	17	65	18.51
TOTAL	424,889	2,193	567	754	872	20.52

Note: Data from Canada British Columbia were not monitored due to lacking denominator (2009 total births)

Table 2: Association rates of defects, among cases with multiple congenital anomalies.
**** p<0.001*

Defect group	N	Exp	Rate ratio	Excess	Poisson
Congenital heart defects	363	238.6	1.5	124.4	***
Other kidney/urinary tract defects	136	81.9	1.7	54.1	***
Other Central Nervous System (CNS) defects	80	44.7	1.8	35.3	***
Esophageal atresia	67	52.1	1.3	14.9	
Anorectal atresia	98	83.2	1.2	14.8	
Other eye defects	32	18.0	1.8	14.0	
Hydrocephaly	71	57.3	1.2	13.7	
Club foot	103	89.9	1.1	13.1	
Polydactyly	75	62.2	1.2	12.8	
Situs inversus	20	7.6	2.6	12.4	***
Hypospadias	47	35.2	1.3	11.8	
Spleen anomalies	18	7.1	2.5	10.9	***
Cleft lip with or without cleft palate	87	76.5	1.1	10.5	
Cystic kidney	31	22.2	1.4	8.8	
Spina bifida	34	25.9	1.3	8.1	
Other ear anomalies	16	8.2	2.0	7.8	
Clefts, other types, and facial anomalies	22	14.8	1.5	7.3	
Other gut atresias	14	7.4	1.9	6.6	
Microcephaly	33	26.7	1.2	6.3	
Vessel anomalies	8	1.9	4.3	6.2	
Gastroschisis	17	11.5	1.5	5.5	
Diaphragmatic hernia	32	26.6	1.2	5.4	
Cystic hygroma	11	6.0	1.8	5.0	
Kidney agenesis	38	33.1	1.1	4.9	
Limb reduction defects, other types	26	21.1	1.2	4.9	
Broncho-pulmonary defects	27	22.3	1.2	4.7	
Ambiguous genitalia	38	34.5	1.1	3.5	
Preaxial limb reduction defects	25	22.0	1.1	3.0	
Omphalocele	39	36.1	1.1	2.9	
Malrotation of gut	9	7.0	1.3	2.0	
Craniostenosis	7	5.1	1.4	1.9	
Duodenal atresia	14	12.2	1.1	1.8	
An-microphthalmia	25	23.4	1.1	1.6	
Sacrum anomalies	4	2.8	1.4	1.2	
Holoprosencephaly	11	10.6	1.0	0.4	
Other gut anomalies	21	20.8	1.0	0.2	
Encephalocele	14	14.6	1.0	-0.6	
Laryngeal/tracheal defects	3	3.6	0.8	-0.6	
Syndactyly	21	21.7	1.0	-0.7	
Other rare defects (sirenomelia, teratoma)	3	3.9	0.8	-0.9	
Exstrophy of cloaca/bladder	4	5.2	0.8	-1.2	
Choanal atresia/stenosis	4	5.5	0.7	-1.5	
Transverse limb reduction defects	14	15.8	0.9	-1.8	
Axial skeleton defects	56	58.2	1.0	-2.2	
Anencephaly	7	11.1	0.6	-4.1	
Cleft palate	47	53.0	0.9	-6.0	
Microtia/anotia	33	39.5	0.8	-6.5	

Table 3: Significant two-defect combinations.

Defect group	N	Exp	Rate ratio	Excess	Poisson
Congenital heart defects	363	238.6	1.5	124.4	***
Other CNS defects + Congenital heart hefects	31	16.5	1.9	14.5	***
Congenital heart defects + Situs inversus	13	2.7	4.8	10.3	***
Other CNS defects + other kidney/					
urinary tract defects	15	5.6	2.7	9.4	***
Microcephaly + other kidney/urinary tract defects	8	2.2	3.6	5.8	***

Comments:

Although cases from Canada British-Columbia were not included for analysis, they were considered for review and description of the cases. Therefore, some of the numbers given below might differ from those shown in Table 3.
In 2009, congenital heart defects (CHD), anomalies of kidney/urinary tract and of the central nervous system (CNS) (excluding neural tube defects and holoprosencephaly) remained among the most frequent defects, individually as well as in combination.
For the two combinations involving CNS anomalies, no specific CHD or kidney/urinary defect appeared as outstanding, and therefore, no pattern was observed. However, three CNS defects predominated: anomalies of the corpus callosum, of the cerebellum (Dandy Walker included), and of the lower spinal cord/canal (cases are listed below). The latter flagged in combination with kidney/urinary tract anomalies (5/16), and infants with this combination variably showed other caudal defects, such as anomalies of the anus, sacrum and genitalia.
The rate of CNS defects seems to be increased, regardless of other associated defects, and their significantly high association rates with CHD and urinary tract anomalies could simply depend on the overall high rates of these two groups of defects.
Although the observed excess of CNS anomalies could be real, it could at least partially depend on the presence of the other associated defects leading to the detection of less conspicuous anomalies, such as those of the corpus callosum. Furthermore, the increased use of prenatal ultrasound routinarily focusing on brain anomalies could also contribute to their excess.

Anomaly of corpus callosum, cerebellum, or lower spinal cord + CHD: 23 cases

Canada British Columbia: cases # 800613,805467,806028,806182
Finland: cases # 5, 44, 68, 74, and 116
Israel: case # 5
Japan: cases # 2153, 3016, and 1104
South America ECLAMC: cases # 41309509, 41801309, 80316109, 80330709, A0504909, and A0517309
USA Atlanta: cases # 16, 18, and 22

Anomaly of corpus callosum or cerebellum + kidney urinary tract anomaly: 6 cases

Israel: cases # 5, and 11
Japan: case # 10132
USA Atlanta: case # 31
South America ECLAMC: cases # A0504909, and 20113909

Anomaly of lower spinal cord/canal + kidney urinary tract anomaly: 5 cases

Finland: cases # 74, 106, and 116
USA Atlanta: cases # 21, and 62

None of the cases combining situs inversus and CHD showed any other defects, except spleen anomalies. Ten of the 13 cases were provided by Japan and it is not clear if the employed term "heterotaxia" in fact indicated the presence of situs inversus, or was applied as an interpretation based on the type of CHD, with or without spleen anomaly.

Microcephaly is coded as such only if no other brain defects are described, and the other kidney/urinary tract defects shown by these infants were highly variable. No pattern could be recognized among cases with this combination.

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

Retinoic acid: 1 case

JAP 7071: Polydactyly of hallux, meatal atresia, hydrocephaly, esophageal and anal atresia, VSD.

Rubella: 5 cases

FIN 236: Left corneal opacity, cataract suspected, ASD secundum, VSD, unspecified anomaly of brain, preauricular tags.

FIN 258: AVSD, anomaly of optic papilla, right microphthalmia, bilateral vesicoureteral reflux, bilateral absence of lacrimal puncta. Micropenis, retention of left testis, laryngomalacia.

USA 55: Corneal opacities and cataracts, small palpebral fissures, ASD, PDA, pulmonary artery stenosis.

SAM A3303709: Microcephaly, anophthalmia, VSD.

SAM 22003109: Microphthalmia, ASD, talipes talovalgus.

Thalidomide: 2 cases

SAM 21709309: Atypical phocomelia of upper limb, complex heart defect.

SAM 21717109: Atypical phocomelia of lower limb, PDA.

Prenatal Diagnosis and Down Syndrome, 2009

Guido Cocchi (Italy: IMER)
Silvia Gualdi (Italy: IMER)

Introduction

Aim of the survey was to assess in time and in the Programme the variability in the use and the spread of prenatal diagnostic techniques and to analyse the impact of elective termination on prevalence rates at birth of Down Syndrome (DS), in Countries where elective abortions are legally performed.

Participation in the Clearinghouse programmes worldwide provides a unique opportunity to analyse international variations in the use of prenatal diagnosis techniques (Chorion Villus Sampling = CVS, Amniocentesis = AC, Cordocentesis = CC), and access to screening, as well as differences in advice and abortion legislation. In addition, repeating this study over time has made it possible to follow the evolution of these techniques and to evaluate the impact of each practice on the prevalence of DS.

2009 Data

In 2009, 23 programmes provided data (Table 1) on 3,193 DS cases, 1,437 of them (45%) terminated on the basis of prenatal diagnoses. The total number of births under surveillance in the 23 programmes was 1,626,707.

The percentage of terminations of pregnancy (ToP) (Table 2) ranged –as in the previous years- from the lowest values in USA: Texas (4%), Iran (8.7%), and Russia: Moscow Region (12.8%), to the highest in the registries of France: REMERA (87.6%) and Czech Republic (80.7%) The 3 French registries all together show the highest percentages of ToP that was in 2009 about 80%. Sweden and Hungary showed a similar value of percentages of termination respectively of 59.1% and 57.6%, while if we consider all together the 4 Italian registries the average percentage of terminations is quite similar i.e. 57.7%

In the European registries that provided a data set of 17 years (1993-2009), a regular increase in the percentage of ToP has been observed, passing from the lowest values of the first three years (1993,1994 and 1995) 41.5%, 45.9%, 48.5% respectively to the highest values of the last three years (2007, 2008 and 2009) respectively 67.6%, 73.3% and 68% (822/1209).

The comparison for 2009 of the percentages of ToPs registered among the 16 Registries of European Countries (61.2%, 1255/2052) versus the 7 Registries of the extra-European Countries (Canada: Alberta, Cuba, Iran, Israel, Russia: Moscow Region and the two USA registries: Texas and Utah) (16.2%, 179/1102) is significantly different ($c2 = 581.6$ $p< 0.0001$).

Terminations are directly related to the maternal age (Table 2): the lower the maternal age class (£29 years) the lower the percentage of terminations; and the higher the maternal age classes (38-39 and ³ 40) the higher the percentages.

The percentage of mothers aged over 35 years (Table 3), has increased year by year. In many registries in 2009 it is over 20% (Israel: IBDMS 21.9%, Sweden 22.3%, France: Paris 31.3% and all the three Italian Registries: IMER and Tuscany show the highest values: 31.7% and 34% respectively.

The higher percentage of ToPS are frequently detected in the registries that show the highest percentages of higher aged mothers. In fact the proportion of pregnancies terminated because of DS were observed among women at higher risk (³35 years old): it was very high in the two French Registries (Paris:78.9.7% and REMERA:93.5%) and in three of the Italian (IMER: 75.7%, Tuscany: 78.6% and BRDCam: 78.9%) where we observe the higher percentage of mothers over 35 years old. There are however some exceptions to this consideration and this is observed in the Czech Registry where in spite of a very high percentage of ToPs (84.1%) in mothers aged ≥35 years we observe a low percentage (13.9%) of the aged mother group. The same consideration could be made for Cuba where the percentage of ToPs is very high (71.6%) despite the low percentage of mothers aged ≥35 years (11.9%). Percentages of ToPs of less than 10% were observed only in the two USA registries : Texas and Utah (5.7%, and 5.4% respectively) (Table 3).

In 2009 the most common technique, used for prenatal diagnosis, was AC (Table 4), with a mean value of 63.8%. CVS, with a mean value of 35.3%, showed a progressive significant increase in the years (p: <0.0001): 18.3% in 1995, 19.3% in 1997, 20.2% in 1999, 22.9% in 2001, 28.6% in 2003, 35% in 2005, 29.8% in 2007 and 35.3in 2009.

In the Registries of France: Strasbourg and Hungary, CVS is the most used technique of prenatal detection with a rate of 70.8% and 68.4% respectively (Table 4).

The Registries, where CVS is most frequently used, show –as expected- the lowest mean gestational ages at pregnancy termination in the older maternal age group (≥35 years) as in Northern Netherland (16.3±3.9), in Canada: Alberta (16.3±2.3) and Czech Republic (16.5±3) (Table 5).

The mean age (wks) of terminations after CVS

diagnosis is heterogeneous and significantly different in the Registries in both maternal age groups. In the younger group (≤34 years) there is a lower limit of around 13 and 16 wks in many Registries, from the lowest in Hungary (13.3±1.1) to the highest in France: Strasbourg (16.3±0.8) (Table 5).

The prevalence at birth of DS has decreased in the majority of the 11 programmes that can provide the rates for all the 17 year period. A significant negative temporal trend was observed above all in the Registries that showed, as expected, an increase in the termination of pregnancies: the Czech Republic (from 7.5 in 1993 to 4.1 per 10,000 in 2009), France: REMERA (from 10.98 in 1993 to 3.4 in 2009), in France: Strasbourg (from 16.7 in 1993 to 7.6 in 2009; Italy: Tuscany (from 11.9 in 1993 to 6.2 in 2009) and Italy: IMER (from 8.9 to 6.7) (Table 6). These are the same Registries that showed the highest rates of ToPs and an increase in the terminations year by year.
Otherwise in the Registries where the terminations are less reported, we can observe an increase in the prevalence at birth in the years as in Canada: Alberta (from 11.4 in 1993 to 14 in 2009) related to the general increase of the maternal age at conception.

Table 1. List of the programs participating in the Prenatal Diagnosis Study in the years.

	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Australia-Western	X	X	X	X	X	X				X	X	X	X	X		X	
Canada-Alberta: ACASS					X	X	X	X	X	X	X	X	X	X	X	X	X
Czech Republic	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Cuba: RECUMAC													X	X	X	X	X
England & Wales	X	X	X	X	X	X	X	X	X	X		X	X	X			
Finland	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
France: REMERA	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
France: Paris	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
France: Strasbourg	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X
Germany: Saxony-Anhalt								X	X	X	X	X	X	X	X	X	X
Hungary																X	X
Iran: TRoCA																X	X
Israel: IBDSP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Italy: Campania	X	X	X	X	X	X	X	X	X	X	X	X	X		X		X
Italy: Emilia Romagna	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Italy: Lombardy																X	
Italy: North-East	X	X	X	X	X	X	X	X	X	X		X	X	X	X		X
Italy: Tuscany	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Norway: MBRN															X	X	X
Northern Netherlands	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Russia: Moscow Region											X	X	X	X	X	X	X
Slovak Republic												X			X	X	X
Sweden								X	X	X	X	X	X		X	X	X
Usa: Atlanta	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Usa: Texas														X	X	X	X
Usa: Utah												X	X	X	X		X
UK Wales												X	X	X	X	X	X
UK Wessex															X		

Table 2. Percentage (%) of terminations among the total number of cases recorded in 2009

Monitoring Program	Maternal Age (years)					
	<= 29	30–34	35–37	38–39	>= 40	Total
Canada-Alberta: ACASS	30.8	16.1	45.0	55.6	35.0	32.1
Cuba: RECUMAC	15.0	14.3	57.5	80.0	81.1	50.3
Czech Republic	73.6	80.0	86.8	79.3	84.1	80.7
Finland	46.7	56.1	57.9	47.8	71.4	58.5
France: REMERA	78.3	85.4	92.1	93.3	95.0	87.6
France: Paris	58.8	68.0	71.4	73.7	87.1	72.8
France: Strasbourg	57.1	66.7	100.0	75.0	40.0	70.6
Germany: Saxony-Anhalt	20.0	80.0	44.4	66.7	75.0	53.9
Hungary	31.6	54.9	88.5	75.9	70.5	57.6
Iran: TRoCA	13.3	25.0	0.0	50.0	33.3	8.5
Israel: IBDSP	14.3	0.0	28.6	0.0	11.1	14.3
Italy: Campania	55.6	80.8	72.7	87.5	79.0	56.6
Italy: Emilia Romagna	50.0	57.1	55.6	100.0	80.0	70.1
Italy: North-East	50.0	64.3	80.0	100.0	57.1	33.7
Italy: Tuscany	50.0	83.3	73.3	85.7	77.8	75.0
Norway	11.1	25.0	36.2		59.1	32.3
Northern Netherlands	40.0	30.8	40.0	100.0	60.0	42.9
Russia: Moscow Region	11.1	0.0	14.3	11.1	30.8	12.8
Slovak Republic	21.1	29.4	25.0	0.0	40.0	24.5
Sweden	37.9	52.6	68.0	73.8	63.5	59.1
USA: Utah	0.0	23.8	22.2	25.0	21.1	17.0
USA: Texas	2.6	2.1	4.0	10.4	4.1	4.0
UK Wales	20.0	64.7	61.9	69.2	63.6	51.7

Table 3. Percentage of mothers aged 35 and over in the monitoring programs participating in the study and percentage of terminations (ToP) in the same group of mothers. Prevalence rate in live and stillbirths (per 10,000) and comparison with the rate after inclusion of ToP

Monitoring Program	% of mothers	% of ToP in mothers	Prevalence rate (per 10,000)	
	aged >=35	aged >=35	LB+SB	LS+SB+ToP
Canada-Alberta: ACASS	15.9	42.9	34.3	60.0
Cuba: RECUMAC	11.9	71.6	18.5	65.1
Czech Republic	13.9	84.1	12.2	76.7
Finland	17.9	68.6	40.5	129.0
France: REMERA	19.1	93.5	5.3	82.3
France: Paris	31.3	78.9	17.6	83.3
France: Strasbourg	18.6	76.2	20.4	85.8
Germany: Saxony-Anhalt	13.9	56.3	29.3	67.0
Hungary	15.0	69.7	22.6	74.8
Iran: TRoCA	8.8	28.6	24.6	34.4
Israel: IBDSP	21.9	16.7	15.9	19.1
Italy: Campania	22.3	78.9	12.0	60.0
Italy: Emilia Romagna	31.7	75.7	13.3	54.7
Italy: North-East	-	56.2	-	-
Italy: Tuscany	34.0	78.6	11.5	53.9
Norway: MBRN	19.6	43.5	31.4	55.7
Northern Netherlands	19.7	52.9	22.4	47.5
Russia: Moscow Region	9.1	18.6	60.2	74.0
Slovak Republic	11.7	23.5	18.2	23.7
Sweden	22.3	65.0	32.3	92.3
USA: Texas	12.1	5.7	50.8	53.9
USA: Utah	9.9	5.4	65.8	69.6
UK Wales	16.1	64.4	28.2	79.3

Table 4 . Down Syndrome techniques of prenatal diagnosis (number of cases) registered in 2009 grouped in maternal age classes

Monitoring Program	<35				35-39				>39				Total			
	CVS	AC	CC	UK	CVS	AC	CC	UK	CVS	AC	CC	UK	CVS	AC	CC	UK
Canada-Alberta: ACASS	6	4	-	3	6	5	-	3	1	4	-	2	13	13	-	8
Czech Republic	37	61	1	-	19	50	-	-	15	22	-	-	71	133	1	-
Finland	18	17	-	2	16	17	-	-	21	18	-	1	55	52	-	3
France: REMERA	24	37	-	1	15	25	-	-	12	27	-	-	51	89	-	1
France: Paris	10	17	-	-	15	14	-	-	13	14	-	-	38	45	-	-
France: Strasbourg	6	2	-	-	11	3	-	-	-	2	-	-	17	7	-	-
Germany: Saxony-Anhalt	1	4	-	-	1	4	-	1	-	3	-	-	2	11	-	1
Hungary	3	1	-	36	6	3	-	36	4	2	-	25	13	6	-	97
Iran: TRoCA	-	-	-	3	-	-	-	1	-	-	-	1	-	-	-	5
Italy: Campania	-	29	-	-	-	27	-	-	-	30	-	-	-	86	-	-
Italy: Emilia Romagna	6	4	-	1	18	14	-	-	12	11	-	1	37	29	-	2
Italy: North-East	7	6	-	-	3	5	-	2	5	3	-	-	15	14	-	4
Italy: Tuscany	5	6	-	1	6	14	1	-	6	14	-	-	17	34	1	1
Northern Netherlands	2	3	-	1	2	4	-	-	2	1	-	-	6	8	-	1
Russia: Moscow Region	-	2	4	-	-	2	2	-	-	3	1	-	-	7	7	-
Sweden	6	30	-	27	13	45	-	38	5	25	-	13	24	101	-	78
USA: Utah	-	5	-	-	-	6	-	-	-	3	1	-	-	14	1	-
Total	**131**	**228**	**5**	**75**	**131**	**238**	**3**	**83**	**96**	**182**	**2**	**43**	**359**	**649**	**10**	**201**

CVS = Chorion Villus sampling
AC = Amniocentesis
CC = Chordocentesis
UK = Unknown

Table 5. Mean gestational age (wks) and Standard Deviation of induced abortions by maternal age group and by technique used by prenatal diagnosis

Monitoring Program	<=34			>=35		
	CVS	AC	Total	CVS	AC	Total
Canada-Alberta: ACASS	14.33±1.03	18.50±0.58	16.00±2.31	14.43±1.51	17.78±1.56	16.31±2.27
Czech Republic	13.43±1.39	18.48±2.64	16.57±3.32	13.26±0.83	18.15±2.31	16.58±3.01
France: REMERA	14.54±1.14	20.97±4.10	18.44±4.54	14.35±1.70	20.52±3.78	18.36±4.40
France: Paris	14.10±1.10	20.88±6.23	18.37±5.96	14.50±2.08	19.86±3.35	17.18±3.86
France: Strasbourg	16.33±0.82	24.00±4.24	18.25±3.96	15.55±2.54	22.00±3.08	17.56±4.05
Germany: Saxony-Anhalt	16.00±0.00	18.75±1.50	18.20±1.79	13.00±0.00	18.43±1.62	17.75±2.43
Hungary	13.33±1.15	20.00±0.00	15.00±3.46	16.10±2.18	20.20±1.64	17.47±2.80
Italy: Campania	-	19.97±2.57	19.97±2.57	-	19.82±1.85	19.85±1.85
Italy: Emilia Romagna	14.50±1.52	19.50±1.29	16.50±2.92	13.70±0.99	18.88±1.27	16.05±2.83
Italy: North-East	14.71±2.63	18.00±1.10	16.23±2.62	14.86±0.90	18.83±0.75	16.69±2.21
Italy: Tuscany	13.40±1.14	18.33±1.51	16.09±2.88	13.25±2.05	18.64±1.66	16.89±3.11
Northern Netherlands	14.50±2.12	19.67±3.06	18.00±4.16	13.25±1.50	18.80±2.39	16.33±3.90
Russia: Moscow Region	-	16.50±0.71	16.50±0.71	-	17.40±0.89	17.40±0.89
USA: Utah	-	16.80±2.49	16.80±2.49	13.00±0.00	15.43±3.60	15.13±3.44

Table 6. Prevalence at birth (per 10,000) in the years of DS in the programs participating in the survey

Programme	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Australia-Western										9.98	8.49	11.03	10.85	11.45		12.57	
Canada-Alberta: ACASS	11.45	11.07	13.15	8.49	11.14	14.02	11.56	14.65	15.20	12.71	19.20	16.52	20.54	13.43	16.42	13.46	14.00
Czech Republic	7.52	7.67	7.26	5.51	5.06	6.72	6.57	5.37	5.51	5.37	6.38	5.51	5.26	3.48	5.08	3.67	4.12
Cuba: RECUMAC													8.31	8.72		7.33	6.16
England & Wales	4.59	4.73	4.91	5.50	6.39	7.18	6.71	6.60	6.27	5.90		7.06	6.94	10.27			
Finland	13.21	12.83	12.94	10.33	10.07	11.33	10.04	11.76	14.18	14.16	12.32	12.25	11.73	14.22	14.08	13.73	12.86
France: REMERA	10.98	10.43	8.91	9.47	9.01	6.83	4.86	5.83	5.85	5.51	4.86	5.86	4.76	6.89	5.19	5.94	3.38
France: Paris	10.61	9.19	7.05	9.67	7.78	10.48	5.24	7.87	7.79	6.20	4.69	5.31	9.15	7.10	8.73	9.41	11.40
France: Strasbourg	16.75	17.87	24.04	17.44	27.95	2.20	4.34	5.62	2.23	2.96	5.18	8.20	5.81	7.17	8.54		7.61
Germany: Saxony-Anhalt	5.79	6.33	7.43	7.86	8.33	13.65	6.09	6.38	8.26	9.08	5.30	9.18	2.90	10.00	8.01	6.19	6.97
Hungary																10.24	8.86
Iran: TRoCA																11.52	14.22
Israel: IBDSP	5.06	5.03	6.32	4.87	9.13	3.28	6.01	4.74	6.15	4.75	6.45	6.66	6.22	0.26	4.38	8.09	5.59
Italy: Campania	10.94	7.63	10.01	9.22	6.74	8.73	6.33	2.99	6.83	5.42	5.17	4.76	2.85		4.28		11.05
Italy: Emilia Romagna	8.97	9.27	10.24	7.97	7.27	9.36	9.58	6.47	6.33	6.15	8.11	5.72	8.24	5.01	6.14	5.66	6.78
Italy: Lombardy																12.14	
Italy: North-East	12.87	10.31	11.46	9.14	7.15	7.23	7.17	6.90	7.83	9.04		6.93	6.41	10.35	9.87		14.26
Italy: Tuscany	11.83	9.80	11.42	6.91	7.34	6.28	6.14	4.90	5.70	3.76	4.00	4.14	4.08	4.64	4.84	6.42	6.21
Norway: MBRN															12.41	10.98	13.26
Northern Netherlands	9.86	5.74	9.38	13.74	11.91	10.03	8.43	6.35	9.32	13.31	5.99	9.40	11.87	8.80	11.31	7.25	11.02
Russia: Moscow Region												10.66	13.64	12.11	10.97	14.84	14.84
Slovak Republic															5.67	7.46	6.53
Sweden							14.01	11.01	14.59	13.31	15..47	10.56	12.69		11.89	12.73	13.39
USA: Atlanta	12.02	13.81	10.93	11.98	10.49	11.46	12.00	11.08	13.25	5.66	13.01	12.98	12.86	10.86	13.11	14.75	
USA: Texas														11.96	13.50	12.72	6.14
USA: Utah												14.01	13.19	11.91	12.83		13.55
Wales												11.69	13.12	10.05	10.40	10.88	11.96
Wessex															15.86		

Alessandra Lisi was a researcher statistician at the ICBDSR Centre in the years 2002 – 2006. Over the years Alessandra's working skill, ethic, grace and kindness made her an increasingly central part of the ICBDSR Centre. Nothing was done at the Centre without her valid help.
She was the only victim of an underground accident that occurred in Rome on October 17, 2006.
We mourn her loss, miss her beyond words and we want remember her with a Prize for a young researcher involved in the field of birth defects and working in one of the ICBDSR Member Registries.

Aim
To recognise a high quality recently published, original peer-reviewed article written in English by a junior researcher and based on research conducted using data from a Clearinghouse Program.

Eligibility
Prize is open to all junior researchers who are no more than two-years post-doctoral level, including those without post-graduate qualifications and will be based on research using data from a Clearinghouse Program.

The prize
One prize of $500, a plaque/ certificate and the summary published in the Annual Report. The winner 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 they are doing at present.

Further information about the Prize application (award criteria, application process, deadline) can be requested to centre@icbdsr.org

Winners of 2011 Award

The Award of the 2010 "Alessandra Lisi Memorial Prize", given by the International Clearinghouse for Birth Defects Monitoring Systems (ICBDSR) to a junior researcher from a Monitoring Program of the ICBDSR, goes to **Narayan P. Iyer** as Author of the high quality, original peer-reviewed article "Outcome of fetuses with Turner syndrome: a 10-year congenital anomaly register based study", published in the Journal of Maternal-Fetal and Neonatal Medicine.

Outcome of fetuses with Turner syndrome: a 10-year congenital anomaly register based study.

Iyer NP, Tucker DF, Roberts SH, Moselhi M, Morgan M, Matthes JW.
Department of Pediatrics, Singleton Hospital, Swansea, UK. niyer@metrohealth.org

J Matern Fetal Neonatal Med. 2012 Jan;25(1):68-73.

Abstract

Objective: To describe the characteristics and outcome of fetuses with Turner syndrome reported to a national congenital anomalies register.

Methods: All cases with a diagnosis of Turner syndrome reported to Congenital Anomaly Register and Information Service for Wales (CARIS) between 1 January 1998 and 31 December 2007 were included. The cases were grouped in five categories based on their outcomes: fetal loss (FL), termination of pregnancy (TOP), live birth (LB), and postnatal (PN) detection and comparison was undertaken between the groups.

Results: One hundred twenty-four cases were reported during the study period. The prevalence of Turner syndrome was 1 in 4901 live female births. Seventy-four percent had 45 X karyotype while the rest had some form of Mosaic Turner karyotype. Pregnancy was terminated in 66% of antenatally diagnosed cases. FL and TOP groups had 92% and 87%, respectively, of 45 X karyotype - far greater than in the LB and PN groups. Increased nuchal thickness was the commonest anomaly noted in antenatal ultrasound and was a predictor for 45 X karyotype, FL, and termination.

Conclusion: Termination was the most common outcome of fetuses diagnosed antenatally with Turner syndrome. This has modified the natural history of Turner syndrome particularly in cases with Mosaic karyotype.

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
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

Synopsis of Contributing Monitoring Systems

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
South America: ECLAMC	Hospital-based Multinational	1977	3 days	500 grams	Not permitted
Spain: ECEMC	Hospital-based National	1979	3 days (***)	24 weeks or 500 grams	Permitted, Not reported
Sweden	Population-based National	1974	28 days	22 weeks	Permitted, Reported
Ukraine: OMNI-Net UBDP	Population-based Regional	2001	1 year	>= 500 grams	Permitted, Reported only for selected malformations
UK-Wales: CARIS	Population-based Regional	2005	1 year	24 weeks	Permitted, Reported
UK-Wessex: WANDA	Population-based Regional	2009	No limit but most < 28 days	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

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 so-called corrected transposition.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Deviations from the ICBDSR Definitions by Registry

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

ICBDSR Definitions of the Reported Malformations

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)

Australia: WARDA
Western Australian Register of Developmental Anomalies

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

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

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

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

Exposure information:
No exposure information is routinely collected.

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

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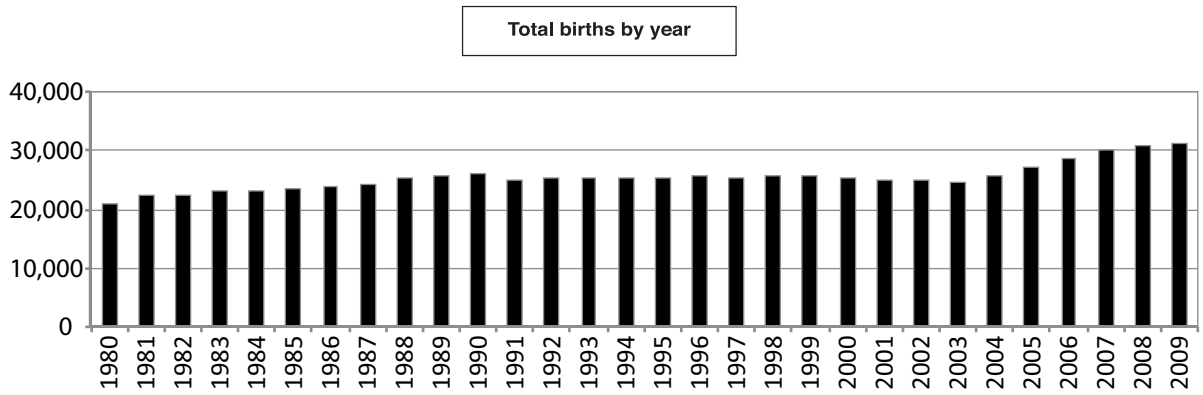
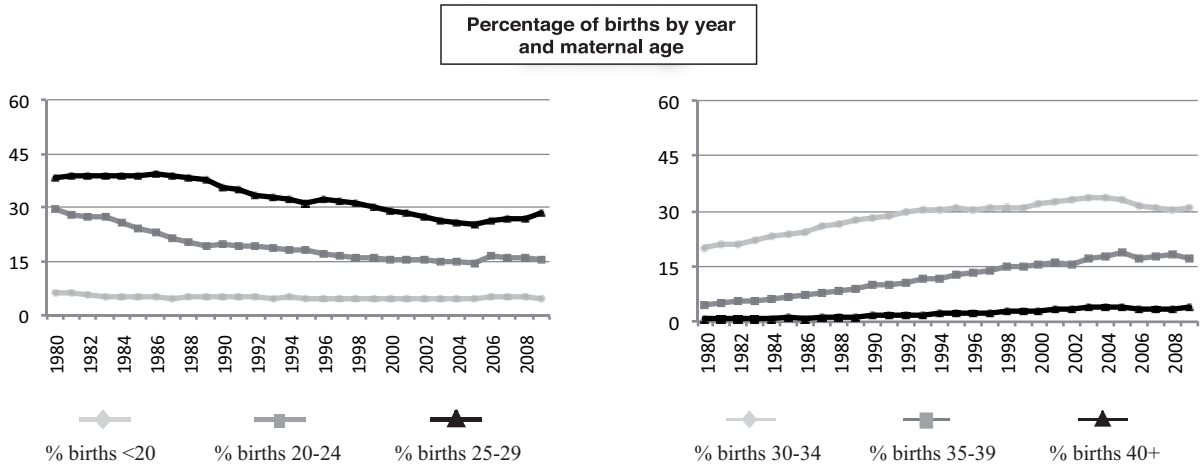
Australia: WARDA





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	50	92.6	Cystic kidney	21	30.0
Spina bifida	27	58.7	Limb reduction defects	22	40.7
Encephalocele	14	77.8	Diaphragmatic hernia	7	28.0
Holoprosencephaly	12	66.7	Omphalocele	32	88.9
Hydrocephaly	40	61.5	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	14	66.7	Trisomy 13	29	96.7
Cleft palate without cleft lip	14	16.7	Trisomy 18	56	83.6
Cleft lip with or without cleft palate	25	22.5	Down syndrome	162	63.3
Renal agenesis	17	43.6			

Total ToPs with births defects = 606 (Ratio ToPs/Births: 6.59 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: WARDA, 2009

Live births (LB)	30,985
Stillbirths (SB)	234
Total births	31,219
Number of terminations of pregnancy (ToP) for birth defects	231

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	15	5.13
Spina bifida	6	1	10	5.45
Encephalocele	1	0	6	2.24
Microcephaly	7	0	1	2.56
Holoprosencephaly	1	1	4	1.92
Hydrocephaly	7	0	11	5.77
Anophthalmos	0	0	1	0.32
Microphthalmos	3	0	0	0.96
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.64
Microtia	4	0	0	1.28
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	10	1	1	3.84
Tetralogy of Fallot	2	0	3	1.60
Hypoplastic left heart syndrome	3	0	4	2.24
Coarctation of aorta	12	0	1	4.16
Choanal atresia, bilateral	2	0	0	0.64
Cleft palate without cleft lip	31	0	5	11.53
Cleft lip with or without cleft palate	27	0	11	12.17
Oesophageal atresia/stenosis with or without fistula	8	3	4	4.80
Small intestine atresia/stenosis	6	0	0	1.92
Anorectal atresia/stenosis	8	1	8	5.45
Undescended testis (36 weeks of gestation or later)	69	0	1	22.42
Hypospadias	85	0	0	27.23
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	8	0	7	4.80
Cystic kidney	18	0	11	9.29
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	24	0	4	8.97
Total Limb reduction defects (include unspecified)	7	0	8	4.80
Transverse	0	0	0	0.00
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	0	0	0.00
Diaphragmatic hernia	6	1	5	3.84
Omphalocele	0	0	17	5.45
Gastroschisis	12	0	0	3.84
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	1	0	0.32
Trisomy 13	1	0	11	3.84
Trisomy 18	3	2	21	8.33
Down syndrome, all ages (include age unknown)	31	3	63	31.07
<20	1	0	1	14.86
20-24	4	0	3	14.73
25-29	6	1	3	11.37
30-34	3	1	10	14.75
35-39	12	1	27	74.89
40-44	5	0	19	216.41
45+	0	0	0	0.00
unknown	0	0	0	---

Australia: WARDA, Previous years rates 1980 - 2009

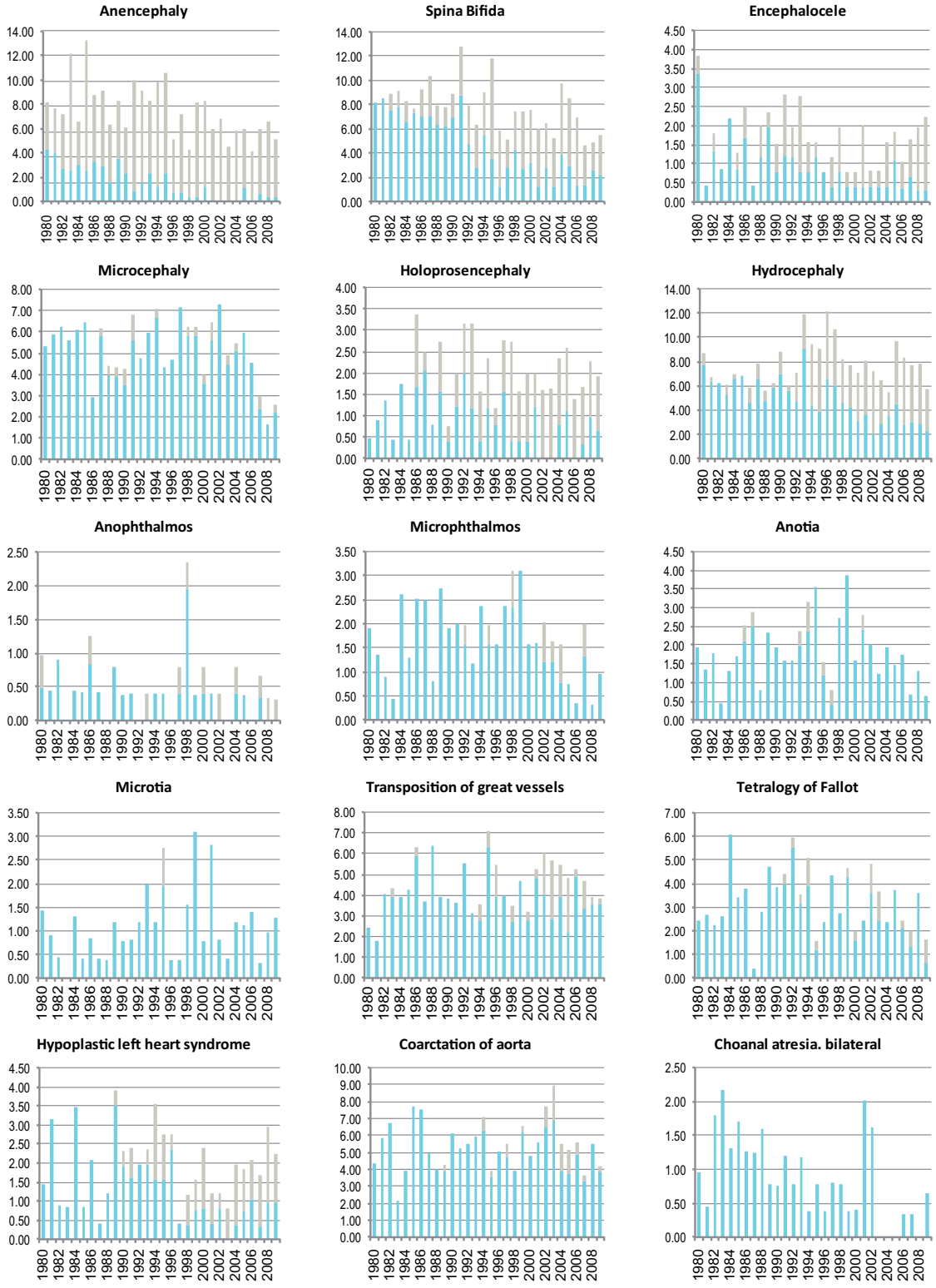
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**111,462**	**122,151**	**127,111**	**127,738**	**125,161**	**147,624**
Anencephaly		8.34	9.09	8.65	7.05	6.31	5.55
Spina bifida		8.61	8.60	8.97	7.52	7.03	6.03
Encephalocele		1.79	1.72	2.12	1.25	1.20	1.76
Microcephaly		5.83	4.83	5.74	5.71	5.59	3.45
Holoprosencephaly		0.99	1.96	2.12	2.11	1.92	1.96
Hydrocephaly		6.91	6.47	8.65	9.55	6.87	7.79
Anophthalmos		0.54	0.57	0.31	0.78	0.48	0.34
Microphthalmos		1.44	1.96	1.89	2.43	1.68	0.88
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		1.35	2.05	2.12	2.51	1.92	1.15
Microtia		0.81	0.65	1.18	1.64	1.20	1.02
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		3.32	4.91	3.93	4.93	5.11	4.47
Tetralogy of Fallot		3.23	3.03	4.56	3.13	3.04	2.64
Hypoplastic left heart syndrome		1.97	1.72	2.52	1.72	1.52	2.17
Coarctation of aorta		4.58	5.65	5.98	5.01	6.47	4.81
Choanal atresia, bilateral		1.35	1.31	0.87	0.63	0.80	0.27
Cleft palate without cleft lip		8.16	8.60	10.31	11.82	11.98	9.21
Cleft lip with or without cleft palate		12.11	14.49	10.07	12.37	13.50	11.65
Oesophageal atresia/stenosis with or without fistula		2.96	3.52	2.67	3.21	3.99	4.61
Small intestine atresia/stenosis		3.05	2.37	2.60	2.74	3.12	2.37
Anorectal atresia/stenosis		5.74	4.91	6.77	5.87	7.03	5.15
Undescended testis (36 weeks of gestation or later)		64.78	67.13	66.63	57.70	49.38	27.43
Hypospadias		26.92	29.80	34.93	35.85	37.15	29.47
Epispadias		0.27	0.41	0.24	0.23	0.16	0.20
Indeterminate sex		0.18	0.25	0.24	0.16	0.32	0.00
Renal agenesis		3.68	3.19	4.41	4.85	4.95	4.47
Cystic kidney		2.51	4.34	7.08	7.36	9.99	7.65
Bladder exstrophy		0.18	0.16	0.31	0.39	0.24	0.14
Polydactyly, preaxial		9.33	10.89	10.62	12.37	11.35	9.69
Total Limb reduction defects (include unspecified)		4.49	5.49	6.61	9.39	8.39	6.84
Transverse		nr	nr	nr	nr	nr	0.00*
Preaxial		nr	nr	nr	nr	nr	0.00*
Postaxial		nr	nr	nr	nr	nr	0.00*
Intercalary		nr	nr	nr	nr	nr	0.00*
Mixed		nr	nr	nr	nr	nr	0.00*
Unspecified		nr	nr	nr	nr	nr	0.00*
Diaphragmatic hernia		3.32	2.70	3.07	4.31	2.96	3.12
Omphalocele		1.88	3.03	3.70	2.97	4.71	4.00
Gastroschisis		1.35	1.80	2.52	4.07	3.04	4.13
Unspecified Omphalocele/Gastroschisis		0.00	0.00	0.00	0.00	0.00	0.00
Prune belly sequence		0.54	0.74	0.55	0.23	0.00	0.07
Trisomy 13		0.72	1.23	1.42	1.72	3.20	3.25
Trisomy 18		1.61	1.80	3.78	5.01	7.27	8.13
Down syndrome, all ages (include age unknown)		11.57	15.23	17.23	19.65	26.45	27.71
<20		4.59	6.47	6.29	6.61	14.10	11.18
20-24		5.23	5.69	7.83	6.55	6.83	9.53
25-29		9.01	7.87	8.38	9.24	13.39	8.86
30-34		11.72	14.35	18.93	16.07	19.61	18.24
35-39		47.15	47.27	38.06	43.67	51.86	61.57
40-44		104.82	257.51	146.54	173.83	156.63	180.47
45+		615.38	461.54	512.82	136.99	582.52	410.26
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

Australia: WARDA

Time trends 1980-2009 (Birth prevalence rates per 10,000)

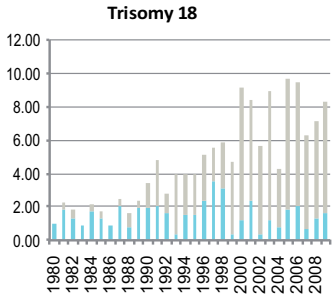


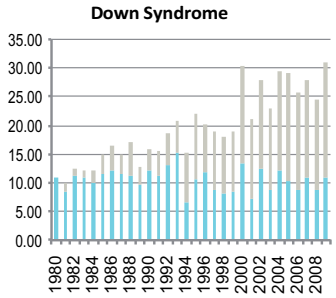
Note: L+S rates, ToP rates

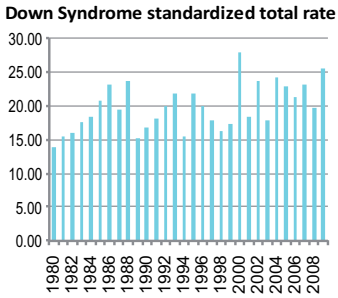
Australia: WARDA

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 1966 as a general Registry for Handicapped Children. This was disbanded in 1980 and continued as a surveillance Programme 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 comprises about 40,000 births per year. The definition of stillbirth is 20 weeks or more or 500 grams or more. The vast majority of births occur in hospital (approximately 97%). In 1997 a special fetal congenital anomalies surveillance system was started to include those fetuses with congenital anomalies who were either spontaneously lost prior to 20 weeks or where there was termination as a result of prenatal diagnosis.

Legislation and funding:
Reporting is voluntary. The system is run by members of the Department of Medical Genetics, Alberta Children's Hospital/University of Calgary reporting to Alberta Vital Statistics and Alberta Health. Funding is from Alberta Ministry of Health.

Sources of ascertainment:
Reports are obtained from physician's notice of birth, live birth and stillbirth registrations, death registrations and a special congenital anomalies reporting form (CARF) from hospitals. This is based on discharge diagnosis, including readmissions for any reason up to one year of age. Additional sources are speciality clinics, such as medical genetics and cytogenetics laboratories.

Exposure information:
None is routine.

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

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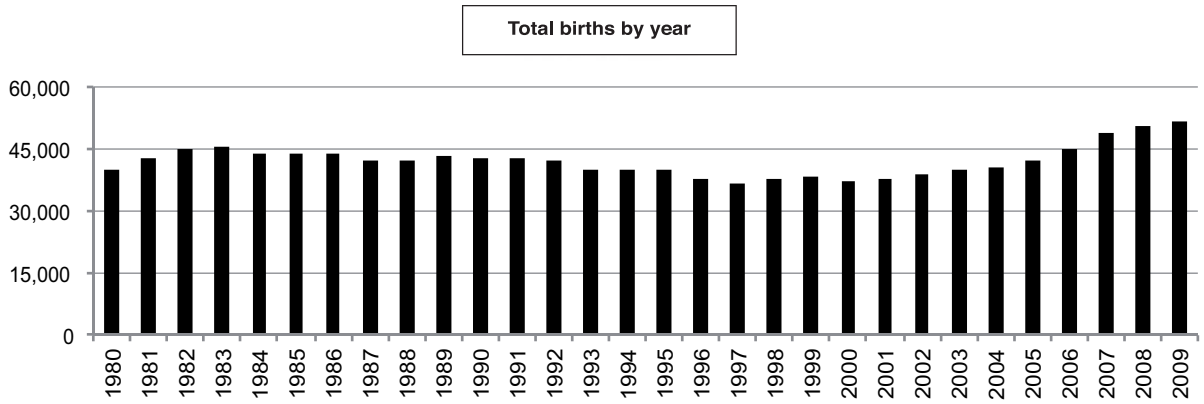
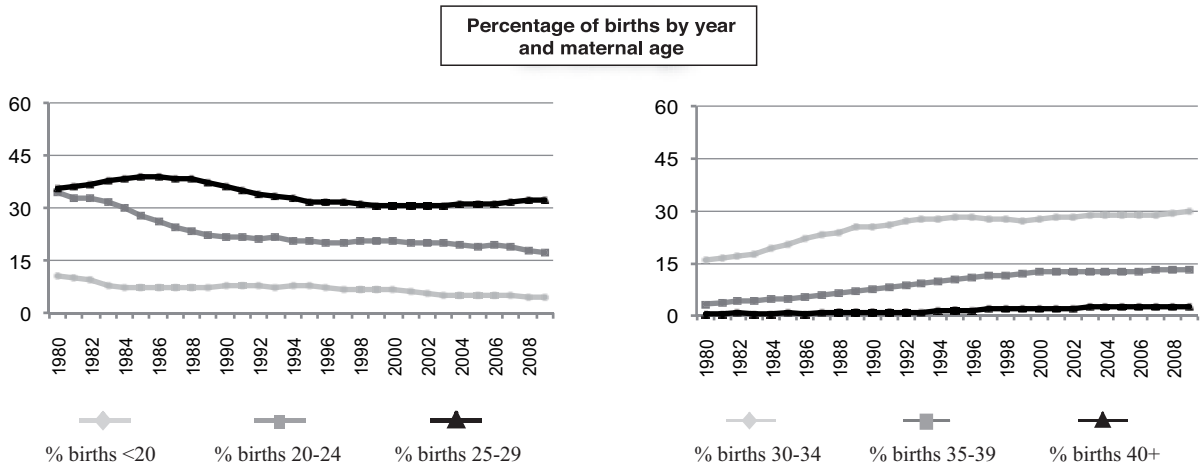
Canada-Alberta: ACASS





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	16	43.2	Cystic kidney	8	7.9
Spina bifida	11	18.0	Limb reduction defects	34	18.3
Encephalocele	3	15.8	Diaphragmatic hernia	4	7.0
Holoprosencephaly	11	28.2	Omphalocele	17	31.5
Hydrocephaly	8	9.0	Gastroschisis	1	1.4
Hypoplastic left heart syndrome	1	2.0	Trisomy 13	26	47.3
Cleft palate without cleft lip	6	6.2	Trisomy 18	36	43.9
Cleft lip with or without cleft palate	9	4.2	Down syndrome	100	31.3
Renal agenesis	2	9.1			

Total ToPs with births defects = 320 (Ratio ToPs/Births: 2.12 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Canada-Alberta: ACASS, 2009

Live births (LB)	51,077
Stillbirths (SB)	343
Total births	51,420
Number of terminations of pregnancy (ToP) for birth defects	137

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	5	9	3.50
Spina bifida	8	11	3	4.28
Encephalocele	5	1	1	1.36
Microcephaly	18	2	2	4.28
Holoprosencephaly	7	2	5	2.72
Hydrocephaly	20	4	4	5.45
Anophthalmos	1	0	0	0.19
Microphthalmos	2	0	1	0.58
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.39
Microtia	13	1	0	2.72
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	11	1	0	2.33
Tetralogy of Fallot	12	1	0	2.53
Hypoplastic left heart syndrome	14	4	1	3.70
Coarctation of aorta	17	3	1	4.08
Choanal atresia, bilateral (§)	7	1	1	1.75
Cleft palate without cleft lip	26	2	3	6.03
Cleft lip with or without cleft palate	61	7	2	13.61
Oesophageal atresia/stenosis with or without fistula	10	1	1	2.33
Small intestine atresia/stenosis	10	1	0	2.14
Anorectal atresia/stenosis	19	5	1	4.86
Undescended testis (36 weeks of gestation or later)	162	1	0	31.70
Hypospadias (*)	110	0	0	21.39
Epispadias	3	0	0	0.58
Indeterminate sex	4	3	1	1.56
Renal agenesis	1	6	0	1.36
Cystic kidney	26	4	5	6.81
Bladder exstrophy	1	1	0	0.39
Polydactyly, preaxial (#)	78	6	13	18.86
Total Limb reduction defects (include unspecified)	33	19	21	14.20
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	15	2	3	3.89
Omphalocele	7	8	8	4.47
Gastroschisis	24	1	1	5.06
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	3	6	11	3.89
Trisomy 18	7	9	15	6.03
Down syndrome, all ages (include age unknown)	60	13	33	20.61
<20	2	0	0	8.40
20-24	3	1	3	7.89
25-29	12	0	5	10.21
30-34	22	5	4	20.31
35-39	12	3	14	42.62
40-44	8	4	7	149.72
45+	1	0	0	116.28
unknown	0	0	0	---

nr = not reported
(§) Choanal atresia, unilateral and bilateral are included
(*) All hypospadias included
(#) All polydactyly included

Canada-Alberta: ACASS, Previous years rates 1980 - 2009

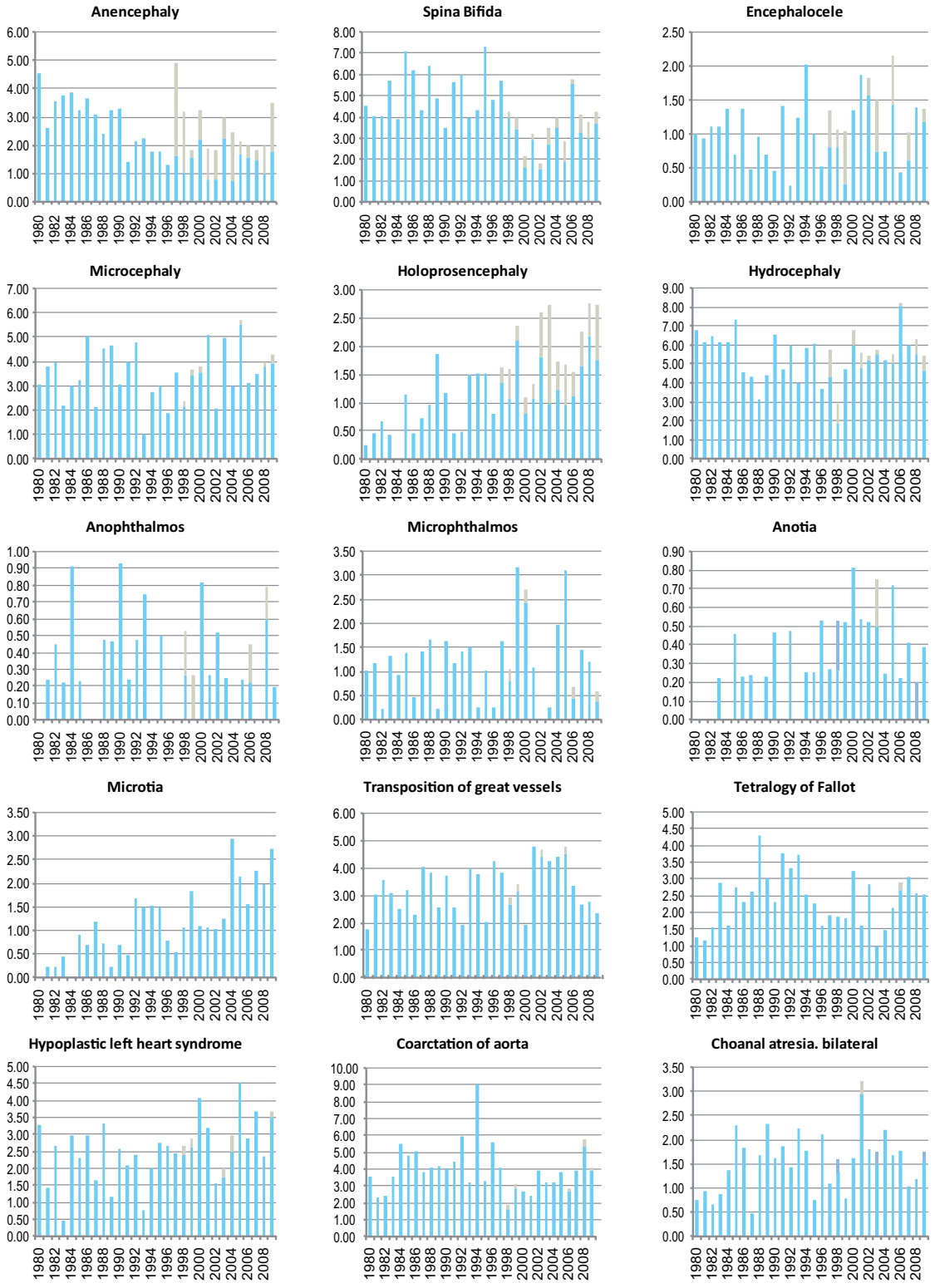
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**216,362**	**214,261**	**207,381**	**190,045**	**193,544**	**237,486**
Anencephaly		3.65	3.13	2.17	2.58	2.48	2.32
Spina bifida		4.44	5.79	4.68	5.21	2.95	4.17
Encephalocele		1.11	0.84	1.06	1.00	1.45	1.26
Microcephaly		3.19	3.92	3.13	2.89	3.77	4.08
Holoprosencephaly		0.37	1.03	1.01	1.58	1.91	2.23
Hydrocephaly		6.33	4.76	5.40	4.63	5.74	6.27
Anophthalmos		0.37	0.23	0.48	0.26	0.36	0.34
Microphthalmos		0.92	1.03	1.21	1.42	1.19	1.35
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.05	0.23	0.24	0.42	0.57	0.38
Microtia		0.18	0.75	1.16	1.16	1.50	2.15
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		2.82	3.17	3.18	3.26	4.03	3.12
Tetralogy of Fallot		1.71	2.99	3.13	1.89	2.02	2.65
Hypoplastic left heart syndrome		2.13	2.29	1.98	2.68	2.74	3.41
Coarctation of aorta		3.47	4.39	5.30	3.58	3.10	4.13
Choanal atresia, bilateral		0.92	1.73	1.78	1.26	2.12	1.47
Cleft palate without cleft lip		6.42	7.05	8.05	8.73	8.11	6.48
Cleft lip with or without cleft palate		10.21	11.99	11.52	11.94	12.56	13.01
Oesophageal atresia/stenosis with or without fistula		2.77	3.17	2.17	2.63	2.07	2.23
Small intestine atresia/stenosis		0.79	1.03	1.40	1.79	1.65	1.52
Anorectal atresia/stenosis		3.24	5.18	5.11	5.16	6.92	4.00
Undescended testis (36 weeks of gestation or later)		26.44	28.24	28.50	21.99	25.78	26.28
Hypospadias		17.15	24.27	24.30	17.89	20.77	21.35
Epispadias		0.55	0.19	0.53	0.32	0.72	0.80
Indeterminate sex		0.37	0.65	1.16	0.95	1.60	1.35
Renal agenesis		2.22	2.85	1.88	1.42	1.65	1.35
Cystic kidney		2.31	3.78	4.82	5.53	8.06	7.03
Bladder exstrophy		0.37	0.19	0.39	0.16	0.52	0.34
Polydactyly, preaxial		9.80	13.95	16.49	11.31	15.76	18.78
Total Limb reduction defects (include unspecified)		6.33	9.01	10.51	10.58	12.14	11.24
Transverse		nr	nr	nr	nr	nr	nr
Preaxial		nr	nr	nr	nr	nr	nr
Postaxial		nr	nr	nr	nr	nr	nr
Intercalary		nr	nr	nr	nr	nr	nr
Mixed		nr	nr	nr	nr	nr	nr
Unspecified		nr	nr	nr	nr	nr	nr
Diaphragmatic hernia		3.37	3.31	2.60	2.74	4.13	3.62
Omphalocele		1.62	2.29	1.88	2.21	2.69	3.12
Gastroschisis		1.34	1.49	1.69	2.47	3.26	5.22
Unspecified Omphalocele/Gastroschisis		0.65	0.42	0.43	0.00	0.00	0.00
Prune belly sequence		0.51	0.28	0.14	0.42	0.36	0.29
Trisomy 13		0.83	0.65	1.21	1.47	1.86	3.20
Trisomy 18		1.66	1.68	2.03	3.74	4.39	5.56
Down syndrome, all ages (include age unknown)		8.92	9.80	11.19	14.47	19.53	21.81
<20		nr	5.59*	4.33	7.35	7.98	7.61
20-24		nr	4.36*	8.05	4.65	6.16	7.30
25-29		nr	6.44*	7.61	6.89	10.69	10.72
30-34		nr	12.20*	13.33	13.52	16.57	16.93
35-39		nr	33.96*	22.44	41.48	47.84	53.52
40-44		nr	106.48*	86.25	134.96	171.65	175.25
45+		nr	0.00*	416.67	396.04	61.73	501.67
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

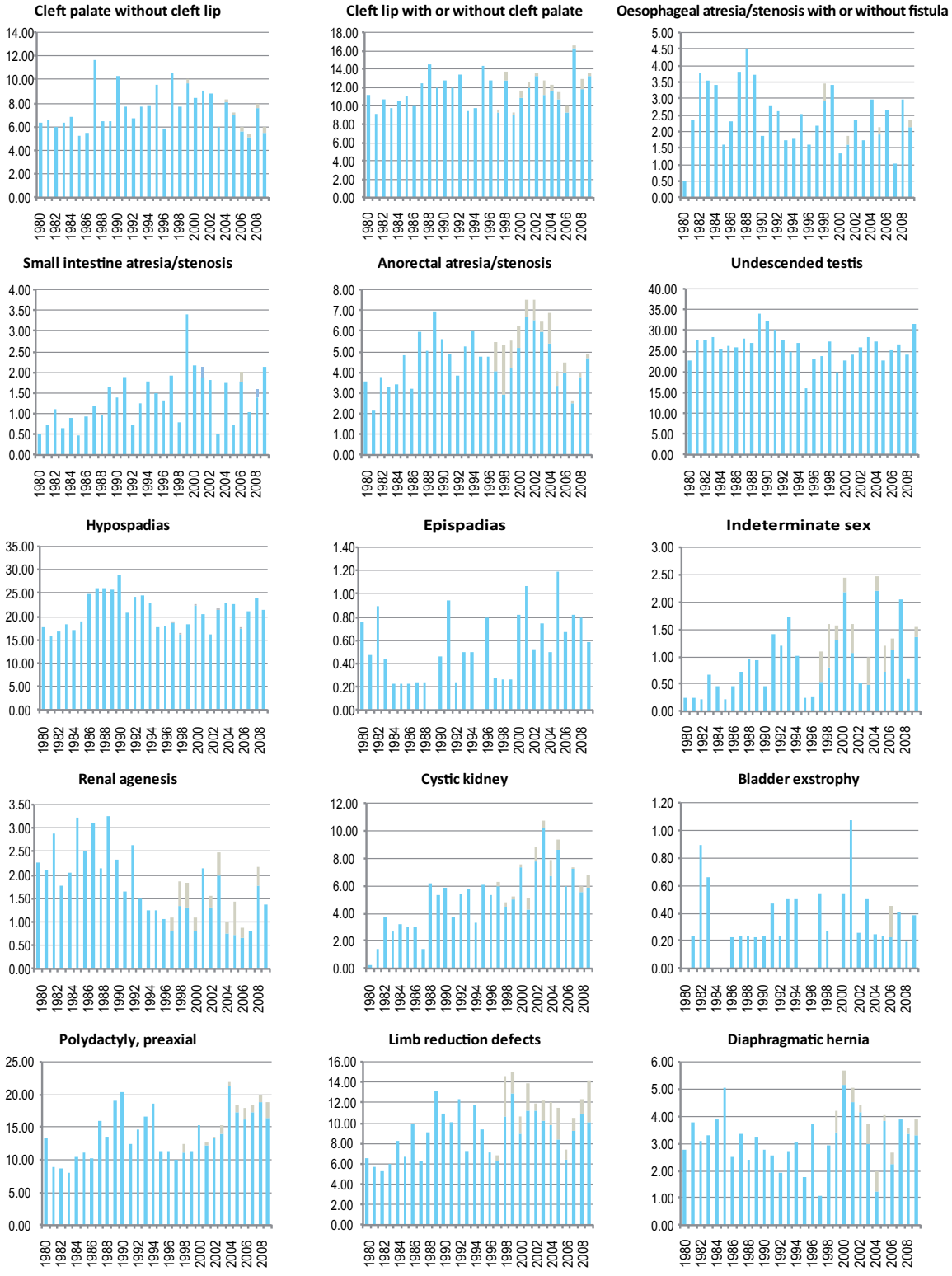
Canada-Alberta: ACASS

Time trends 1980-2009 (Birth prevalence rates per 10,000)



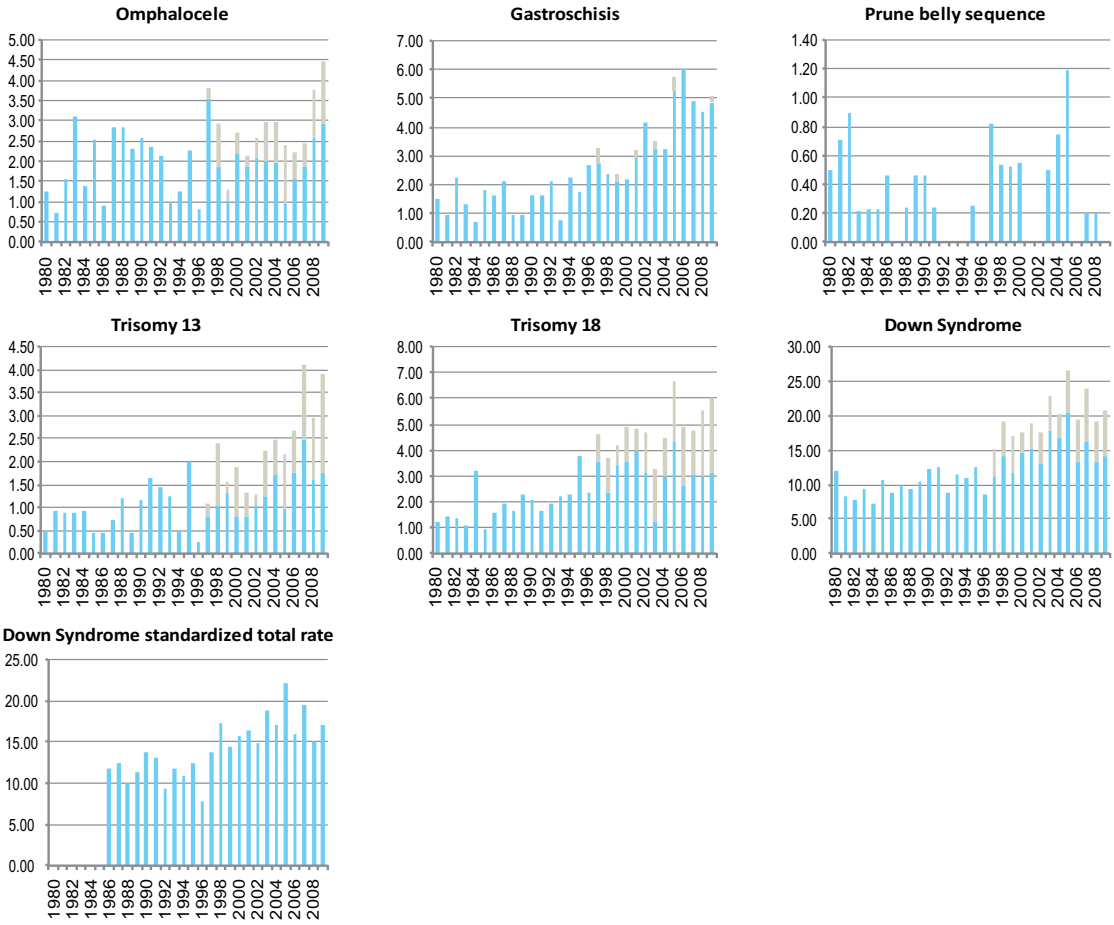
Note: L+S rates, ToP rates

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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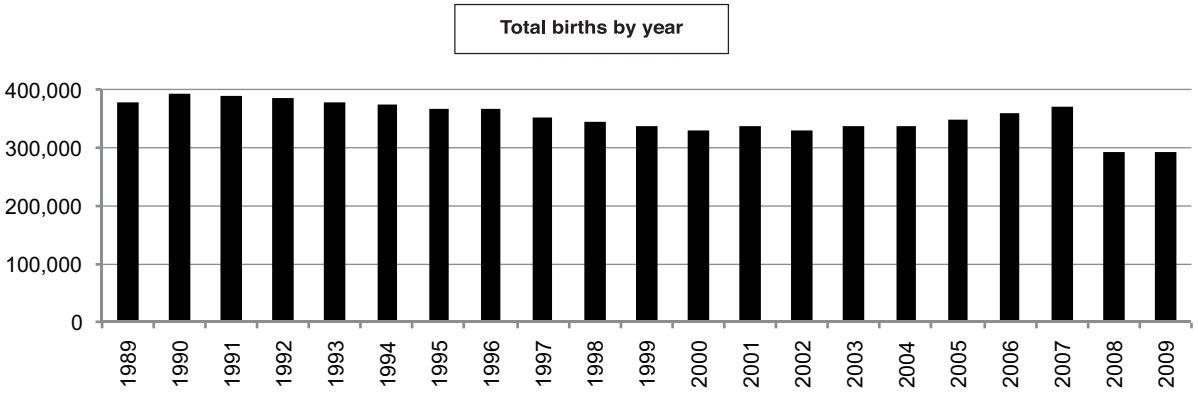
Canada National: CCASS



Canada National: CCASS, 2009

Live births (LB)	290,067
Stillbirths (SB)	2,245
Total births	292,312
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	22	nr	1.27
Spina bifida	76	23	nr	3.39
Encephalocele	12	4	nr	0.55
Microcephaly	98	3	nr	3.46
Holoprosencephaly	17	10	nr	0.92
Hydrocephaly	122	29	nr	5.17
Anophthalmos	3	2	nr	0.17
Microphthalmos	20	0	nr	0.68
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	2	0	nr	0.07
Microtia	32	1	nr	1.13
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	141	8	nr	5.10
Tetralogy of Fallot	88	5	nr	3.18
Hypoplastic left heart syndrome	63	7	nr	2.39
Coarctation of aorta	123	3	nr	4.31
Choanal atresia, bilateral	67	0	nr	2.29
Cleft palate without cleft lip	162	2	nr	5.61
Cleft lip with or without cleft palate	293	10	nr	10.37
Oesophageal atresia/stenosis with or without fistula	63	0	nr	2.16
Small intestine atresia/stenosis	110	2	nr	3.83
Anorectal atresia/stenosis	108	5	nr	3.87
Undescended testis (36 weeks of gestation or later) (*)	1,007	1	nr	34.48
Hypospadias	789	1	nr	27.03
Epispadias	24	0	nr	0.82
Indeterminate sex	37	1	nr	1.30
Renal agenesis	118	25	nr	4.89
Cystic kidney	185	14	nr	6.81
Bladder exstrophy	4	1	nr	0.17
Polydactyly, preaxial	374	5	nr	12.97
Total Limb reduction defects (include unspecified)	108	6	nr	3.90
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	76	7	nr	2.84
Omphalocele	60	15	nr	2.57
Gastroschisis	123	8	nr	4.48
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	21	19	nr	1.37
Trisomy 18	33	35	nr	2.33
Down syndrome, all ages (include age unknown)	350	71	nr	14.40
<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 = not reported
(*) No information on gestational age

Canada National: CCASS, Previous years rates 1989 - 2009

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

	1974-1979	1980-1984	1985-1989*	1990-1994	1995-1999	2000-2004	2005-2009
Total births			**375,840**	**1,918,123**	**1,768,280**	**1,670,796**	**1,658,158**
Anencephaly			2.16	1.90	1.26	1.07	1.00
Spina bifida			7.96	6.88	5.16	3.08	2.96
Encephalocele			1.46	1.36	0.98	0.73	0.67
Microcephaly			5.40	5.49	5.51	5.16	3.62
Holoprosencephaly			nr	nr	nr	nr	0.78*
Hydrocephaly			7.21	7.05	6.80	5.55	4.64
Anophthalmos			0.19	0.35	0.25	0.25	0.14
Microphthalmos			0.82	1.07	1.01	0.83	0.68
Unspecified Anophthalmos/Microphthalmos			nr	nr	nr	nr	nr
Anotia			nr	nr	nr	nr	0.06*
Microtia			nr	nr	nr	nr	0.92*
Unspecified Anotia/Microtia			nr	nr	nr	nr	nr
Transposition of great vessels			3.86	4.57	5.76	4.79	4.76
Tetralogy of Fallot			4.98	4.48	5.24	4.13	3.76
Hypoplastic left heart syndrome			2.87	2.86	2.86	2.84	2.41
Coarctation of aorta			5.51	5.34	6.10	5.25	4.72
Choanal atresia, bilateral			2.66	2.03	2.46	2.83	2.10
Cleft palate without cleft lip			6.70	7.17	7.46	6.94	6.85
Cleft lip with or without cleft palate			10.70	11.37	10.98	9.43	9.09
Oesophageal atresia/stenosis with or without fistula			3.35	3.47	3.40	2.91	2.47
Small intestine atresia/stenosis			3.49	3.47	3.60	3.91	3.82
Anorectal atresia/stenosis			5.75	5.13	5.03	4.35	3.69
Undescended testis (36 weeks of gestation or later)			36.03	34.29	32.65	38.32	36.16
Hypospadias			27.11	26.78	27.20	nr	26.45*
Epispadias			nr	nr	nr	nr	0.64*
Indeterminate sex			0.88	0.67	0.69	0.98	1.30
Renal agenesis			5.27	4.97	5.05	5.06	5.00
Cystic kidney			4.47	4.96	6.10	7.07	6.97
Bladder exstrophy			0.35	0.45	0.37	0.35	0.31
Polydactyly, preaxial			12.21	11.88	11.92	13.96	13.79
Total Limb reduction defects (include unspecified)			4.76	4.65	4.18	3.82	3.45
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	3.77	3.63	3.31	3.20
Omphalocele			3.72	5.67	6.14*	nr	2.19*
Gastroschisis			nr	nr	nr	nr	4.06*
Unspecified Omphalocele/Gastroschisis			nr	nr	nr	nr	nr
Prune belly sequence			nr	nr	nr	nr	nr
Trisomy 13			1.41	1.13	1.11	1.20	1.18
Trisomy 18			2.02	2.18	2.39	2.21	2.48
Down syndrome, all ages (include age unknown)			12.13	13.21	13.62	14.49	14.41
<20			nr	nr	nr	nr	nr
20-24			nr	nr	nr	nr	nr
25-29			nr	nr	nr	nr	nr
30-34			nr	nr	nr	nr	nr
35-39			nr	nr	nr	nr	nr
40-44			nr	nr	nr	nr	nr
45+			nr	nr	nr	nr	nr
unknown			---	---	---	---	---

nr = not reported
* data include less than 5 years

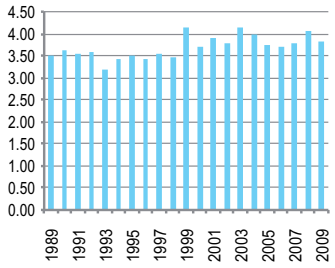
Canada National: CCASS

Time trends 1989-2009 (Birth prevalence rates per 10,000)

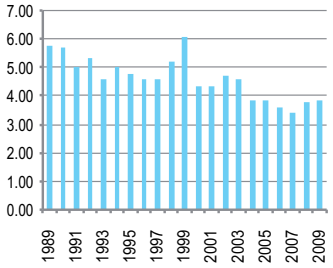
Note: L+S rates

Canada National: CCASS

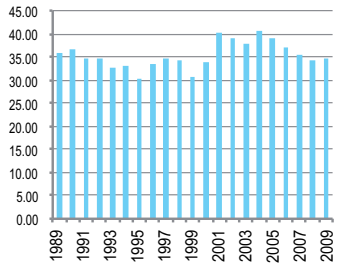
Small intestine atresia/stenosis



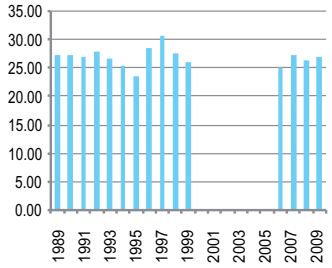
Anorectal atresia/stenosis



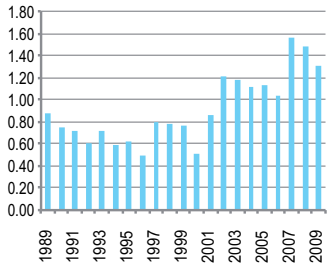
Undescended testis



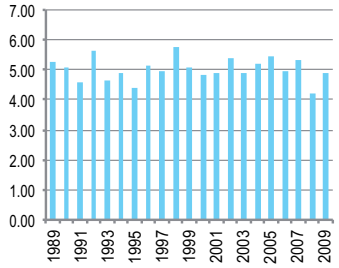
Hypospadias



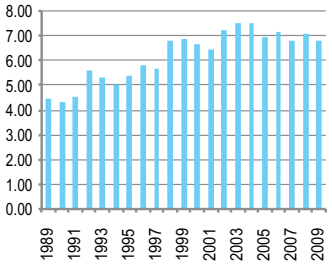
Indeterminate sex



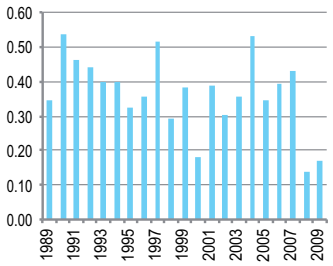
Renal agenesis



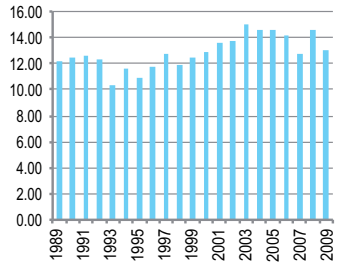
Cystic kidney



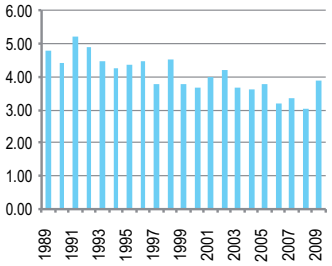
Bladder exstrophy



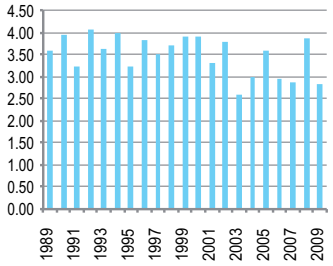
Polydactyly, preaxial



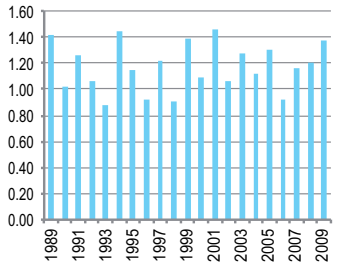
Limb reduction defects



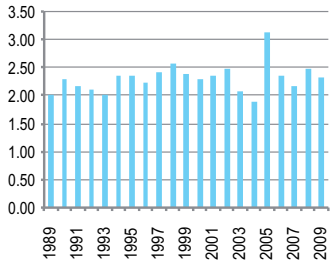
Diaphragmatic hernia



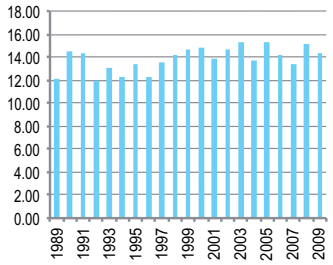
Trisomy 13



Trisomy 18



Down Syndrome



Note: L+S rates

Chile-Maule: RRMC-SSM

Regional Register Congenital Malformational Maule Health Service

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

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

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

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

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

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

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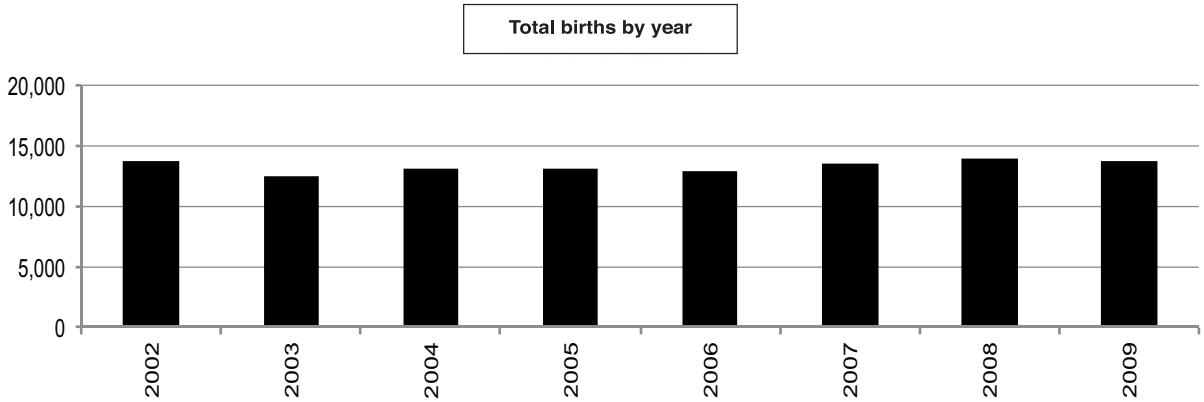
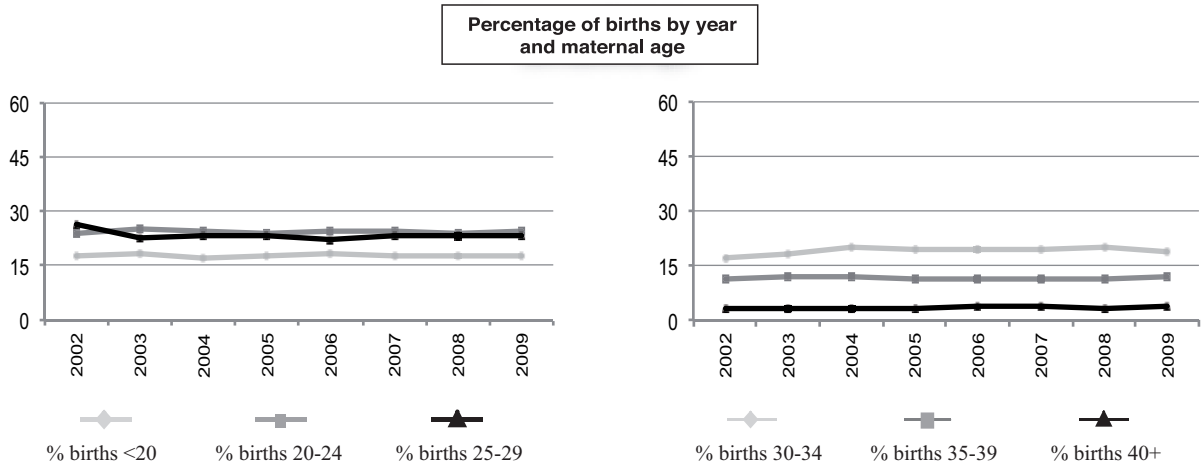
rrmc@ssmaule.cl

Rosa GajardoAbarza
Dirección Servicio de Salud del Maule
Maule Region
Phone: 56-71-411698
E-mail: rgajardo@ssmaule.cl

Chile-Maule: RRMC-SSM





Chile-Maule: RRMC-SSM, 2009

Live births (LB)	13,568
Stillbirths (SB)	82
Total births	13,650
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	0		0.00
Spina bifida	0	0		0.00
Encephalocele	0	0		0.00
Microcephaly	1	0		0.73
Holoprosencephaly	0	0		0.00
Hydrocephaly	5	1		4.40
Anophthalmos	0	0		0.00
Microphthalmos	0	0		0.00
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	5	0		3.66
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	0	0		0.00
Tetralogy of Fallot	0	1		0.73
Hypoplastic left heart syndrome	0	0		0.00
Coarctation of aorta	0	0		0.00
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	4	0		2.93
Cleft lip with or without cleft palate	10	0		7.33
Oesophageal atresia/stenosis with or without fistula	1	0		0.73
Small intestine atresia/stenosis	4	0		2.93
Anorectal atresia/stenosis	2	0		1.47
Undescended testis (36 weeks of gestation or later)	15	0		10.99
Hypospadias	11	0		8.06
Epispadias	0	0		0.00
Indeterminate sex	0	0		0.00
Renal agenesis	2	0		1.47
Cystic kidney	2	0		1.47
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	20	1		15.38
Total Limb reduction defects (include unspecified)	5	0		3.66
Transverse	0	0		0.00
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	0	0		0.00
Mixed	0	0		0.00
Unspecified	5	0		3.66
Diaphragmatic hernia	2	0		1.47
Omphalocele	0	0		0.00
Gastroschisis	4	0		2.93
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	0		0.73
Trisomy 18	2	0		1.47
Down syndrome, all ages (include age unknown)	27	2		21.25
<20	2	0		8.39
20-24	3	0		8.98
25-29	0	0		0.00
30-34	8	0		30.78
35-39	8	1		55.18
40-44	6	1		135.92
45+	0	0		0.00
unknown	0	0		---

Chile-Maule: RRMC-SSM, Previous years rates 2002 - 2009

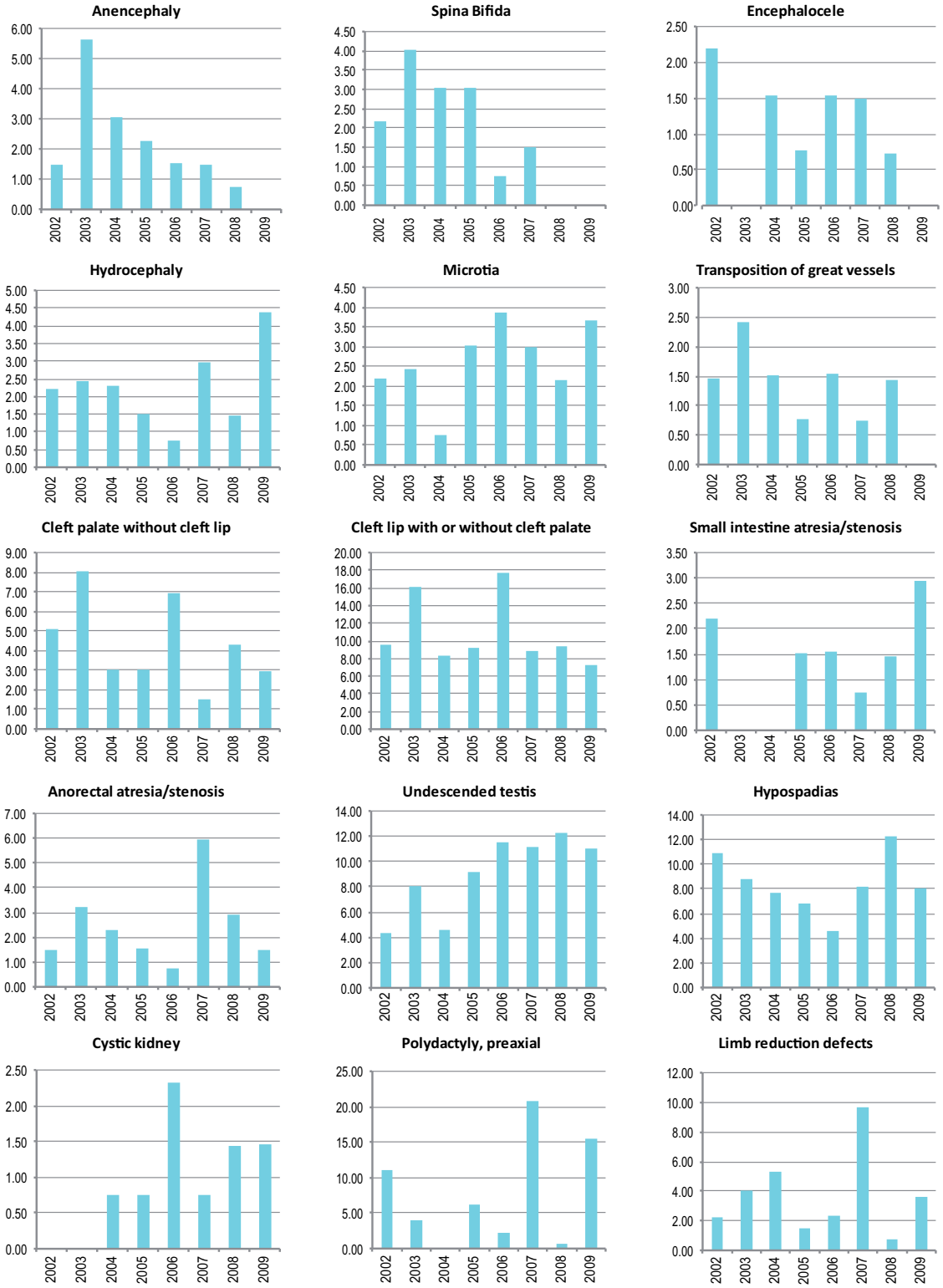
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-19992000-2004*	2005-2009
Total births					**39,229**	**67,026**
Anencephaly					3.31	1.19
Spina bifida					3.06	1.04
Encephalocele					1.27	0.90
Microcephaly					1.78	1.04
Holoprosencephaly					0.51	0.00
Hydrocephaly					2.29	2.24
Anophthalmos					0.25	0.00
Microphthalmos					1.02	0.30
Unspecified Anophthalmos/Microphthalmos					0.00	0.00
Anotia					0.51	0.00
Microtia					1.78	3.13
Unspecified Anotia/Microtia					0.00	0.00
Transposition of great vessels					1.78	0.90
Tetralogy of Fallot					1.27	0.90
Hypoplastic left heart syndrome					0.25	0.45
Coarctation of aorta					0.00	0.30
Choanal atresia, bilateral					1.02	0.00
Cleft palate without cleft lip					5.35	3.73
Cleft lip with or without cleft palate					11.22	10.44
Oesophageal atresia/stenosis with or without fistula					0.51	1.49
Small intestine atresia/stenosis					0.76	1.64
Anorectal atresia/stenosis					2.29	2.54
Undescended testis (36 weeks of gestation or later)					5.61	11.04
Hypospadias					9.18	8.06
Epispadias					0.00	0.15
Indeterminate sex					0.76	0.60
Renal agenesis					0.76	1.34
Cystic kidney					0.25	1.34
Bladder exstrophy					0.25	0.00
Polydactyly, preaxial					5.10	9.10
Total Limb reduction defects (include unspecified)					3.82	3.58
Transverse					2.55	1.64
Preaxial					0.00	0.30
Postaxial					0.00	0.00
Intercalary					0.00	0.15
Mixed					0.00	0.00
Unspecified					0.00	1.49
Diaphragmatic hernia					0.76	1.34
Omphalocele					1.27	1.49
Gastroschisis					1.53	2.24
Unspecified Omphalocele/Gastroschisis					0.00	0.45
Prune belly sequence					0.25	0.30
Trisomy 13					1.78	0.75
Trisomy 18					0.51	2.09
Down syndrome, all ages (include age unknown)					22.18	21.04
<20					1.44	11.70
20-24					4.17	7.99
25-29					10.46	3.87
30-34					17.87	15.32
35-39					63.46	59.32
40-44					227.27	167.67
45+					444.44	245.90
unknown					---	---

* data include less than 5 years

Chile-Maule: RRMC-SSM

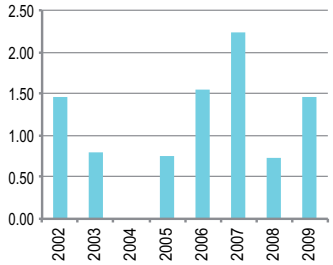
Time trends 2002-2009 (Birth prevalence rates per 10,000)



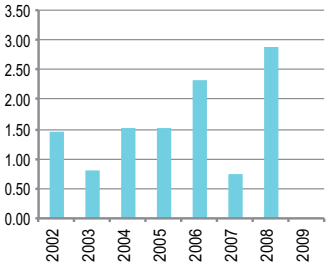
Note: L+S rates

Chile-Maule: RRMC-SSM

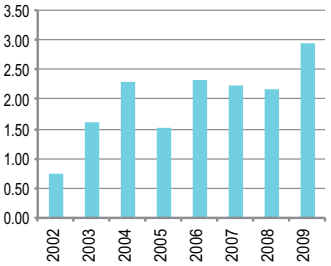
Diaphragmatic hernia



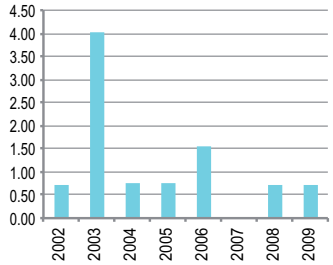
Omphalocele



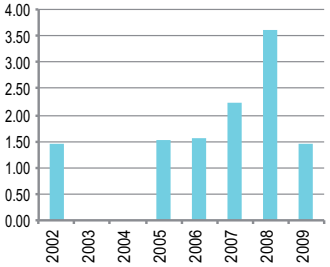
Gastroschisis



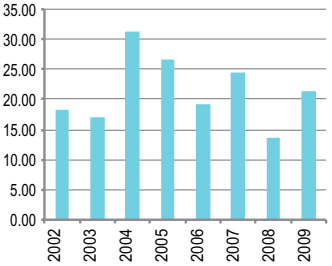
Trisomy 13



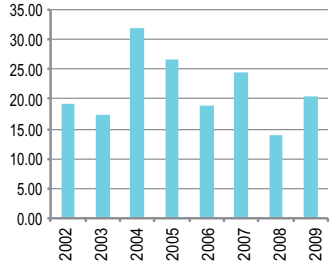
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Colombia-Bogota: BCMSP

Bogota Congenital Malformations Surveillance Program

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

Size and Coverage:
The program is hospital based register. In 2001 surveillance began in one hospital of Bogotá D.C. and coverage has been expanded up to a total of 45 hospitals in 2011. In the past year approximately 104,700 births were monitored.

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

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

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

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

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Colombia-Bogota: BCMSP, 2009

Live births (LB)	30,385
Stillbirths (SB)	101
Total births	30,486
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	4	1		1.64
Spina bifida	5	1		1.97
Encephalocele	0	0		0.00
Microcephaly	5	0		1.64
Holoprosencephaly	1	1		0.66
Hydrocephaly	11	1		3.94
Anophthalmos	1	0		0.33
Microphthalmos	2	0		0.66
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	22	0		7.22
Unspecified Anotia/Microtia	1	0		0.33
Transposition of great vessels	1	0		0.33
Tetralogy of Fallot	2	0		0.66
Hypoplastic left heart syndrome	2	1		0.98
Coarctation of aorta	1	0		0.33
Choanal atresia, bilateral	3	0		0.98
Cleft palate without cleft lip	16	1		5.58
Cleft lip with or without cleft palate	26	0		8.53
Oesophageal atresia/stenosis with or without fistula	10	0		3.28
Small intestine atresia/stenosis	4	1		1.64
Anorectal atresia/stenosis	9	1		3.28
Undescended testis (36 weeks of gestation or later)	11	0		3.61
Hypospadias	12	0		3.94
Epispadias	2	0		0.66
Indeterminate sex	7	0		2.30
Renal agenesis	3	1		1.31
Cystic kidney	4	0		1.31
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	51	0		16.73
Total Limb reduction defects (include unspecified)	10	0		3.28
Transverse	0	0		0.00
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	0	0		0.00
Mixed	0	0		0.00
Unspecified	9	9		5.90
Diaphragmatic hernia	3	0		0.98
Omphalocele	0	0		0.00
Gastroschisis	5	0		1.64
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	0	0		0.00
Trisomy 18	1	2		0.98
Down syndrome, all ages (include age unknown)	33	0		10.82
<20	3	0		5.81
20-24	2	0		2.61
25-29	4	0		5.49
30-34	1	0		1.90
35-39	14	0		48.88
40-44	6	0		73.71
45+	3	0		361.45
unknown	0	0		---

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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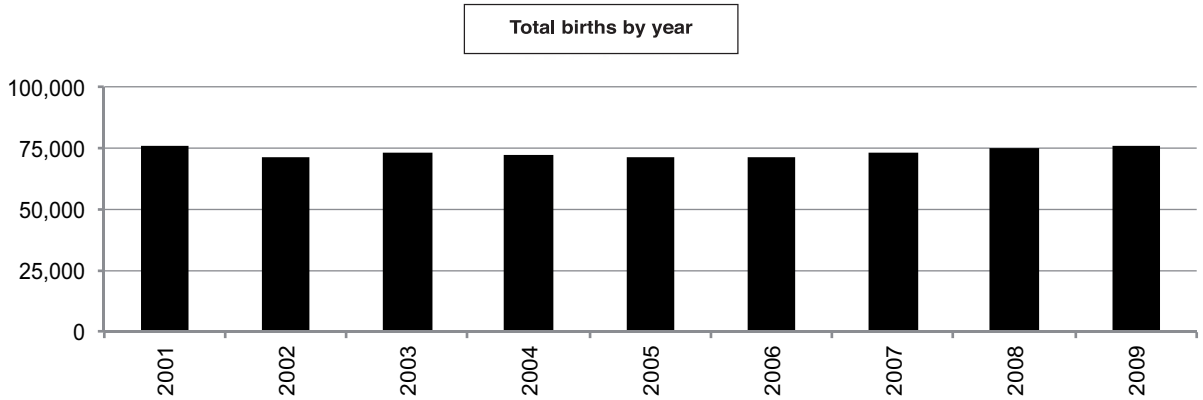
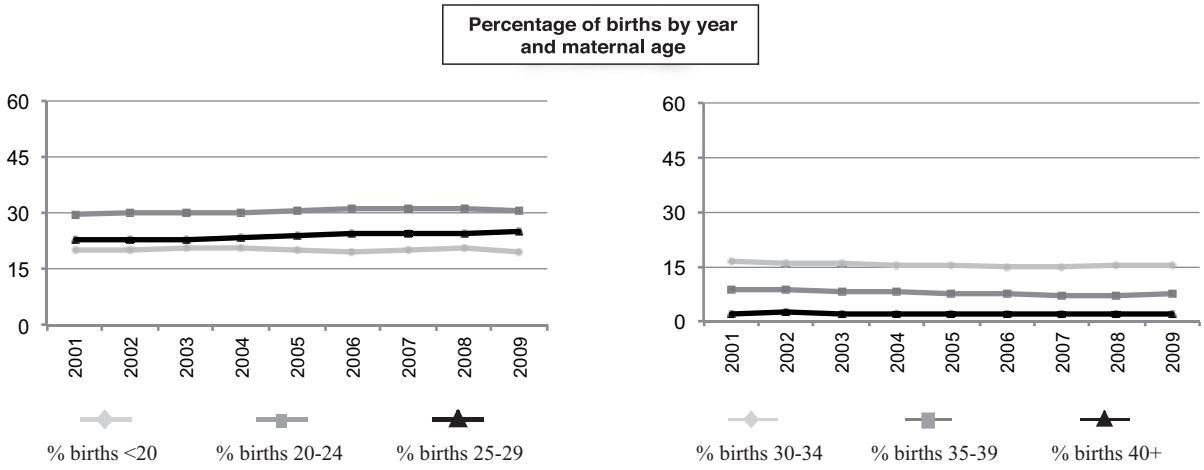
Costa Rica: CREC





Costa Rica: CREC, 2009

Live births (LB)	75,000
Stillbirths (SB)	493
Total births	75,493
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	7	1		1.06
Spina bifida	22	0		2.91
Encephalocele	8	0		1.06
Microcephaly	19	0		2.52
Holoprosencephaly	1	0		0.13
Hydrocephaly	14	1		1.99
Anophthalmos	1	0		0.13
Microphthalmos	3	0		0.40
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	6	1		0.93
Microtia	18	0		2.38
Unspecified Anotia/Microtia	2	0		0.26
Transposition of great vessels	4	0		0.53
Tetralogy of Fallot	8	0		1.06
Hypoplastic left heart syndrome	7	0		0.93
Coarctation of aorta	8	0		1.06
Choanal atresia, bilateral	1	0		0.13
Cleft palate without cleft lip	19	0		2.52
Cleft lip with or without cleft palate	49	0		6.49
Oesophageal atresia/stenosis with or without fistula	17	0		2.25
Small intestine atresia/stenosis	3	0		0.40
Anorectal atresia/stenosis	17	0		2.25
Undescended testis (36 weeks of gestation or later)	104	1		13.91
Hypospadias	48	1		6.49
Epispadias	1	0		0.13
Indeterminate sex	9	0		1.19
Renal agenesis	6	0		0.79
Cystic kidney	9	1		1.32
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial (*)	89	0		11.79
Total Limb reduction defects (include unspecified)	32	1		4.37
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	11	1		1.59
Omphalocele	12	0		1.59
Gastroschisis	17	1		2.38
Unspecified Omphalocele/Gastroschisis	nr	nr		nr
Prune belly sequence	3	0		0.40
Trisomy 13	2	0		0.26
Trisomy 18	8	0		1.06
Down syndrome, all ages (include age unknown)	75	1		10.07
<20	7	1		5.45
20-24	9	0		3.94
25-29	7	0		3.74
30-34	13	0		11.32
35-39	22	0		39.42
40-44	14	0		98.31
45+	0	0		0.00
unknown	3	0		---

nr = not reported
(*) All polydactyly included.

Costa Rica: CREC, Previous years rates 2001 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994	1995-19992000-2004*	2005-2009
Total births					**292,320**	**366,261**
Anencephaly					1.40	1.23
Spina bifida					3.63	2.87
Encephalocele					0.51	0.79
Microcephaly					1.13	1.91
Holoprosencephaly					0.38	0.55
Hydrocephaly					2.33	2.78
Anophthalmos					0.21	0.25
Microphthalmos					0.34	0.57
Unspecified Anophthalmos/Microphthalmos					0.00	0.00
Anotia					0.24	0.79
Microtia					2.33	2.10
Unspecified Anotia/Microtia					0.00	0.05
Transposition of great vessels					0.07	0.55
Tetralogy of Fallot					0.82	0.79
Hypoplastic left heart syndrome					0.38	0.52
Coarctation of aorta					0.34	0.49
Choanal atresia, bilateral					0.27	0.25
Cleft palate without cleft lip					2.39	2.78
Cleft lip with or without cleft palate					7.12	6.80
Oesophageal atresia/stenosis with or without fistula					1.27	1.72
Small intestine atresia/stenosis					0.55	0.55
Anorectal atresia/stenosis					2.46	2.87
Undescended testis (36 weeks of gestation or later)					10.02	10.46
Hypospadias					6.09	6.77
Epispadias					0.03	0.11
Indeterminate sex					1.54	1.69
Renal agenesis					0.58	0.90
Cystic kidney					0.34	1.04
Bladder exstrophy					0.07	0.03
Polydactyly, preaxial					6.88	10.95
Total Limb reduction defects (include unspecified)					4.96	4.45
Transverse					nr	nr
Preaxial					nr	nr
Postaxial					nr	nr
Intercalary					nr	nr
Mixed					nr	nr
Unspecified					nr	nr
Diaphragmatic hernia					1.51	1.58
Omphalocele					0.41	1.37
Gastroschisis					1.54	2.02
Unspecified Omphalocele/Gastroschisis					0.21	0.00
Prune belly sequence					0.24	0.41
Trisomy 13					1.30	0.52
Trisomy 18					0.89	1.04
Down syndrome, all ages (include age unknown)					8.45	8.71
<20					5.88	4.13
20-24					5.13	3.91
25-29					4.02	4.03
30-34					5.82	6.70
35-39					25.29	31.33
40-44					67.88	94.69
45+					113.90	208.82
unknown					---	---

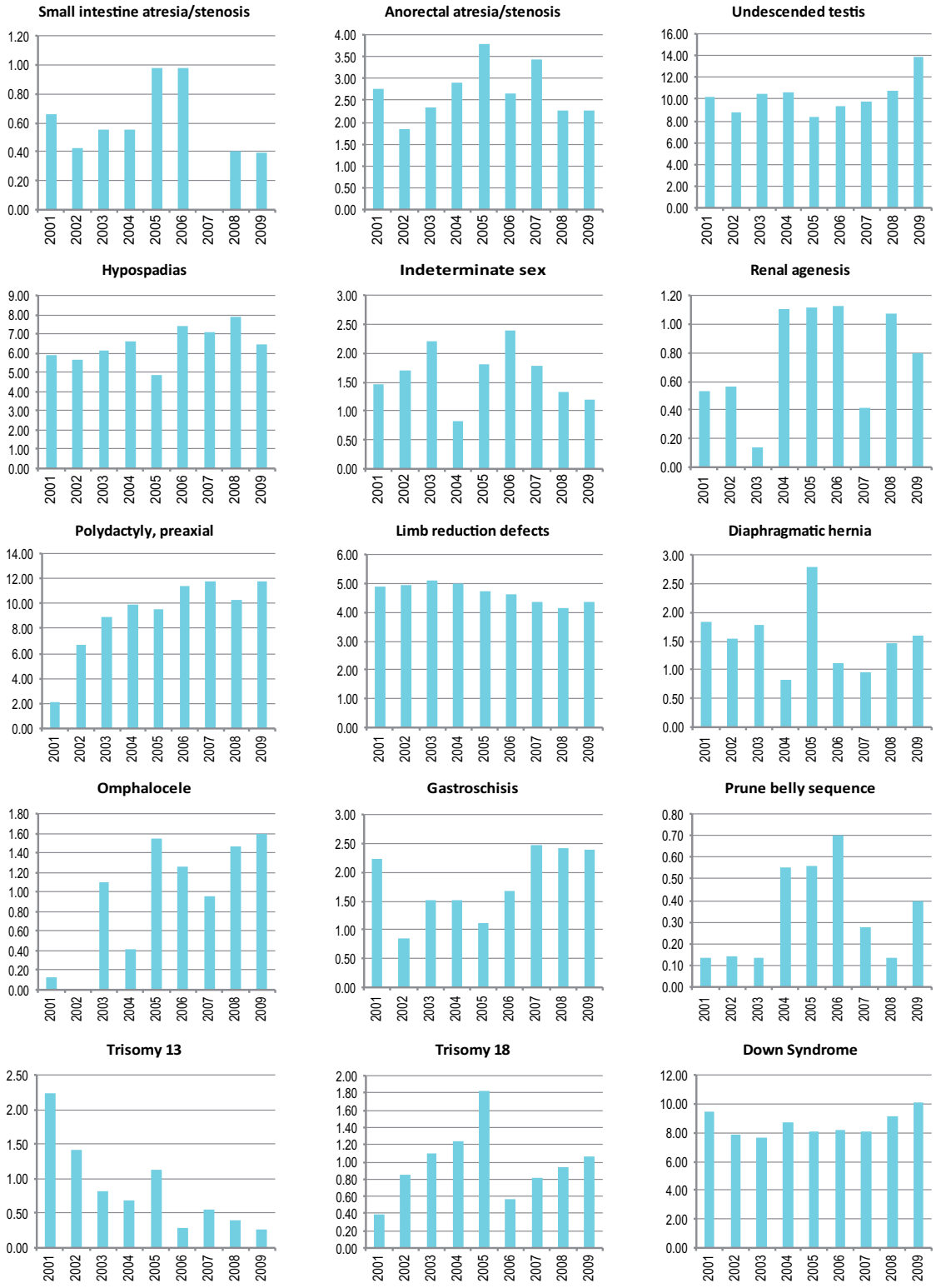
nr = not reported
* data include less than 5 years

Costa Rica: CREC

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

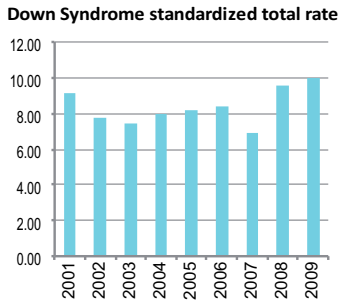
Note: L+S rates

Costa Rica: CREC



Note: L+S rates

Costa Rica: CREC



Note: L+S rates

Cuba: RECUMAC
Cuban Register of Congenital Malformation

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

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

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

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

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

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

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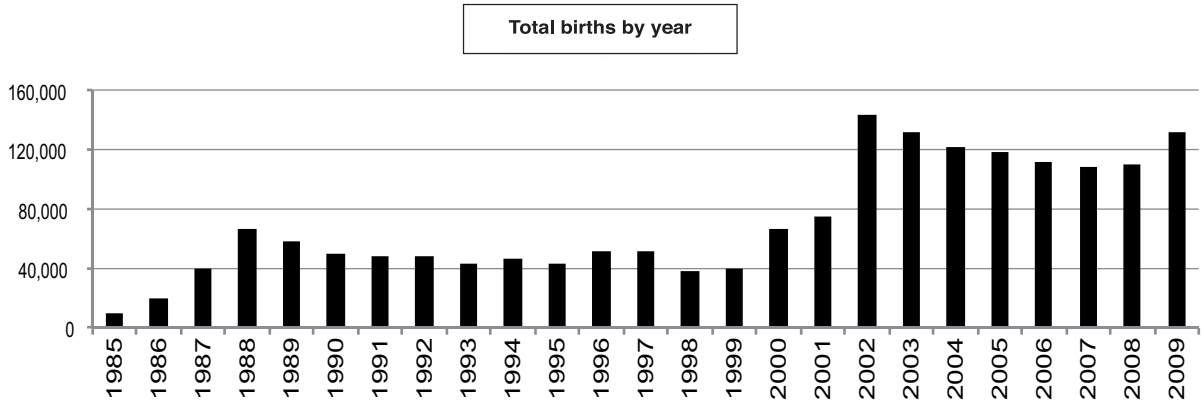
Cuba: RECUMAC



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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	120	98.4	Cystic kidney	121	86.4
Spina bifida	160	87.9	Limb reduction defects	22	28.9
Encephalocele	57	91.9	Diaphragmatic hernia	74	75.5
Holoprosencephaly	35	87.5	Omphalocele	80	95.2
Hydrocephaly	274	88.7	Gastroschisis	231	95.5
Hypoplastic left heart syndrome	73	91.3	Trisomy 13	32	76.2
Cleft palate without cleft lip	8	12.3	Trisomy 18	58	81.7
Cleft lip with or without cleft palate	47	28.1	Down syndrome	208	45.5
Renal agenesis	42	77.8			

Total ToPs with births defects = 3,795 (Ratio ToPs/Births: 10.86 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Cuba: RECUMAC, 2009

Live births (LB)	130,037
Stillbirths (SB)	1,460
Total births	131,497
Number of terminations of pregnancy (ToP) for birth defects	1,414

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	71	5.48
Spina bifida	10	0	30	3.04
Encephalocele	2	0	25	2.05
Microcephaly	2	0	4	0.46
Holoprosencephaly	1	0	16	1.29
Hydrocephaly	13	2	84	7.53
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.08
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.23
Microtia	9	0	0	0.68
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	0	14	1.52
Tetralogy of Fallot	5	0	21	1.98
Hypoplastic left heart syndrome	4	0	31	2.66
Coarctation of aorta	3	0	0	0.23
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	21	0	8	2.21
Cleft lip with or without cleft palate	42	0	19	4.64
Oesophageal atresia/stenosis with or without fistula	20	2	16	2.89
Small intestine atresia/stenosis	10	1	32	3.27
Anorectal atresia/stenosis	1	0	2	0.23
Undescended testis (36 weeks of gestation or later)	29	0	0	2.21
Hypospadias	103	0	0	7.83
Epispadias	2	0	0	0.15
Indeterminate sex	6	0	0	0.46
Renal agenesis	5	0	15	1.52
Cystic kidney	6	0	43	3.73
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	17	0	0	1.29
Total Limb reduction defects (include unspecified)	13	0	3	1.22
Transverse	5	0	0	0.38
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.08
Mixed	0	0	0	0.00
Unspecified	7	0	0	0.53
Diaphragmatic hernia	11	0	22	2.51
Omphalocele	0	0	30	2.28
Gastroschisis	1	0	89	6.84
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	8	0.61
Trisomy 18	4	0	24	2.13
Down syndrome, all ages (include age unknown)	81	3	85	12.85
<20	7	0	1	3.96
20-24	15	1	3	4.43
25-29	10	1	2	4.14
30-34	17	1	3	9.82
35-39	22	0	43	49.51
40-44	6	0	29	145.71
45+	1	0	1	136.99
unknown	3	0	3	---

Cuba: RECUMAC, Previous years rates 1985 - 2009

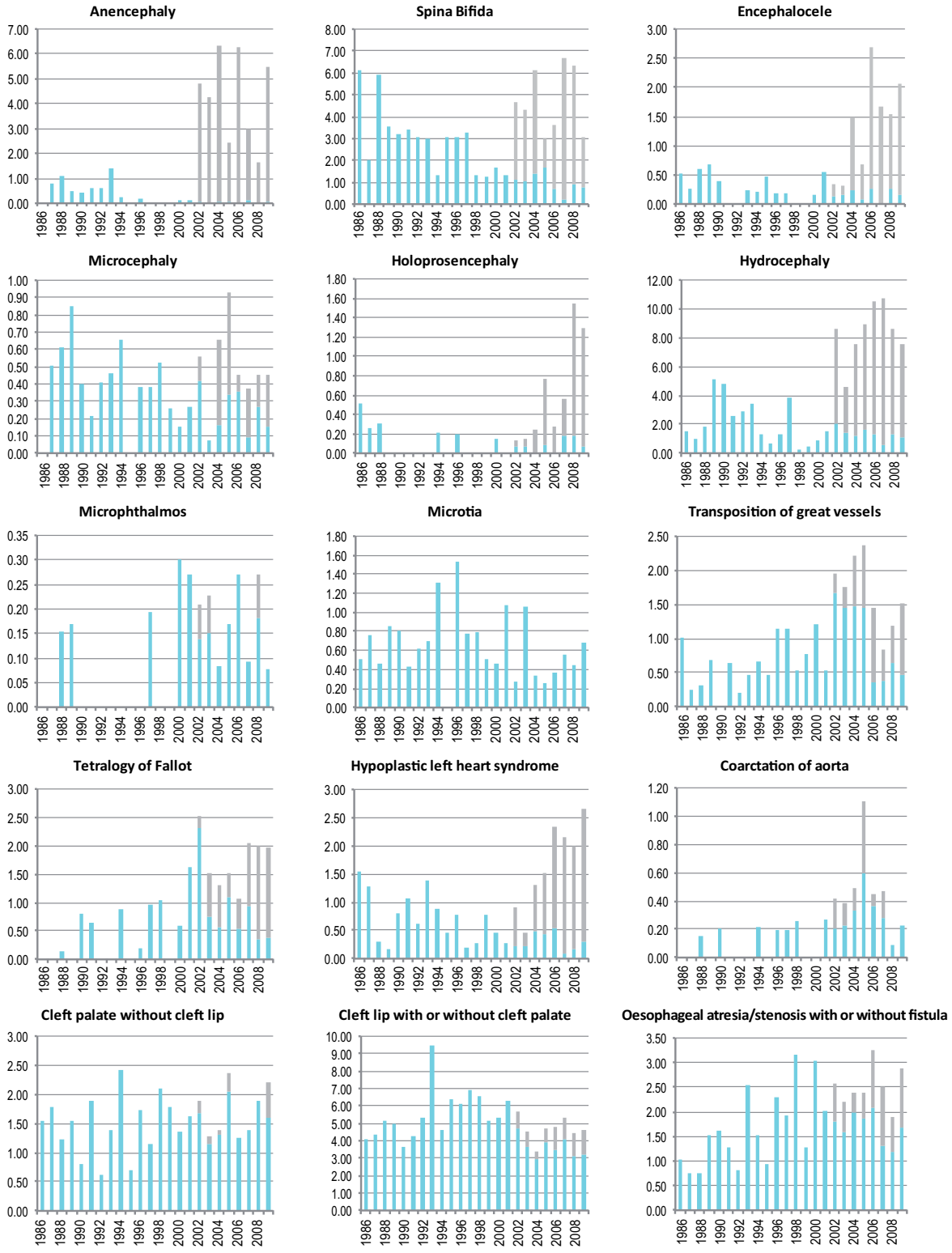
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births			**191,491**	**234,691**	**223,546**	**536,617**	**578,401**
Anencephaly			0.78	0.64	0.04	3.80	3.82
Spina bifida			4.86	2.81	2.51	4.08	4.44
Encephalocele			0.52	0.17	0.18	0.60	1.73
Microcephaly			0.63	0.43	0.31	0.37	0.54
Holoprosencephaly			0.26	0.04	0.04	0.15	0.90
Hydrocephaly			2.98	3.03	1.48	5.48	9.18
Anophthalmos			0.00	0.09	0.00	0.13	0.07
Microphthalmos			0.10	0.00	0.04	0.20	0.17
Unspecified Anophthalmos/Microphthalmos			0.00	0.00	0.00	0.02	0.05
Anotia			0.00	0.00	0.04	0.11	0.14
Microtia			0.78	0.77	0.76	0.61	0.47
Unspecified Anotia/Microtia			0.00	0.00	0.00	0.02	0.05
Transposition of great vessels			0.47	0.38	0.85	1.68	1.49
Tetralogy of Fallot			0.05	0.47	0.45	1.64	1.73
Hypoplastic left heart syndrome			0.63	0.94	0.49	0.75	2.14
Coarctation of aorta			0.05	0.09	0.13	0.35	0.47
Choanal atresia, bilateral			0.26	0.00	0.18	0.20	0.05
Cleft palate without cleft lip			1.46	1.41	1.48	1.53	1.85
Cleft lip with or without cleft palate			4.80	5.37	6.26	4.92	4.75
Oesophageal atresia/stenosis with or without fistula			1.10	1.53	1.92	2.42	2.59
Small intestine atresia/stenosis			0.84	0.77	0.63	1.32	2.58
Anorectal atresia/stenosis			1.31	1.53	1.07	1.29	1.12
Undescended testis (36 weeks of gestation or later)			4.86	3.71	2.95	2.68	2.52
Hypospadias			13.58	15.13	10.33	7.70	9.32
Epispadias			0.21	0.30	0.13	0.09	0.26
Indeterminate sex			0.21	0.17	0.18	0.39	0.40
Renal agenesis			0.63	0.21	0.36	0.69	1.26
Cystic kidney			1.20	1.11	0.40	1.90	3.68
Bladder exstrophy			0.21	0.13	0.18	0.13	0.07
Polydactyly, preaxial			0.10	0.21	0.40	0.76	0.85
Total Limb reduction defects (include unspecified)			2.77	2.77	2.24	2.40	2.09
Transverse			1.15	0.89	0.67	0.60	0.74
Preaxial			0.00	0.00	0.00	0.04	0.03
Postaxial			0.00	0.00	0.00	0.00	0.03
Intercalary			0.00	0.00	0.00	0.11	0.14
Mixed			0.00	0.00	0.00	0.24	0.36
Unspecified			0.00	0.94	0.49	1.08	0.86
Diaphragmatic hernia			1.57	1.41	1.30	1.60	2.66
Omphalocele			0.68	0.81	0.31	1.43	2.21
Gastroschisis			0.31	0.43	0.40	2.16	6.09
Unspecified Omphalocele/Gastroschisis			0.16	0.00	0.00	0.22	0.07
Prune belly sequence			0.10	0.13	0.00	0.02	0.07
Trisomy 13			0.37	0.60	0.31	0.80	1.30
Trisomy 18			0.10	0.26	0.45	0.52	1.88
Down syndrome, all ages (include age unknown)			8.15	7.71	7.38	9.22	12.53
<20			nr	nr	nr	nr	3.96*
20-24			nr	nr	nr	nr	4.43*
25-29			nr	nr	nr	nr	4.14*
30-34			nr	nr	nr	nr	9.82*
35-39			nr	nr	nr	nr	49.51*
40-44			nr	nr	nr	nr	145.71*
45+			nr	nr	nr	nr	136.99*
unknown			---	---	---	---	---

nr = not reported
* data include less than 5 years

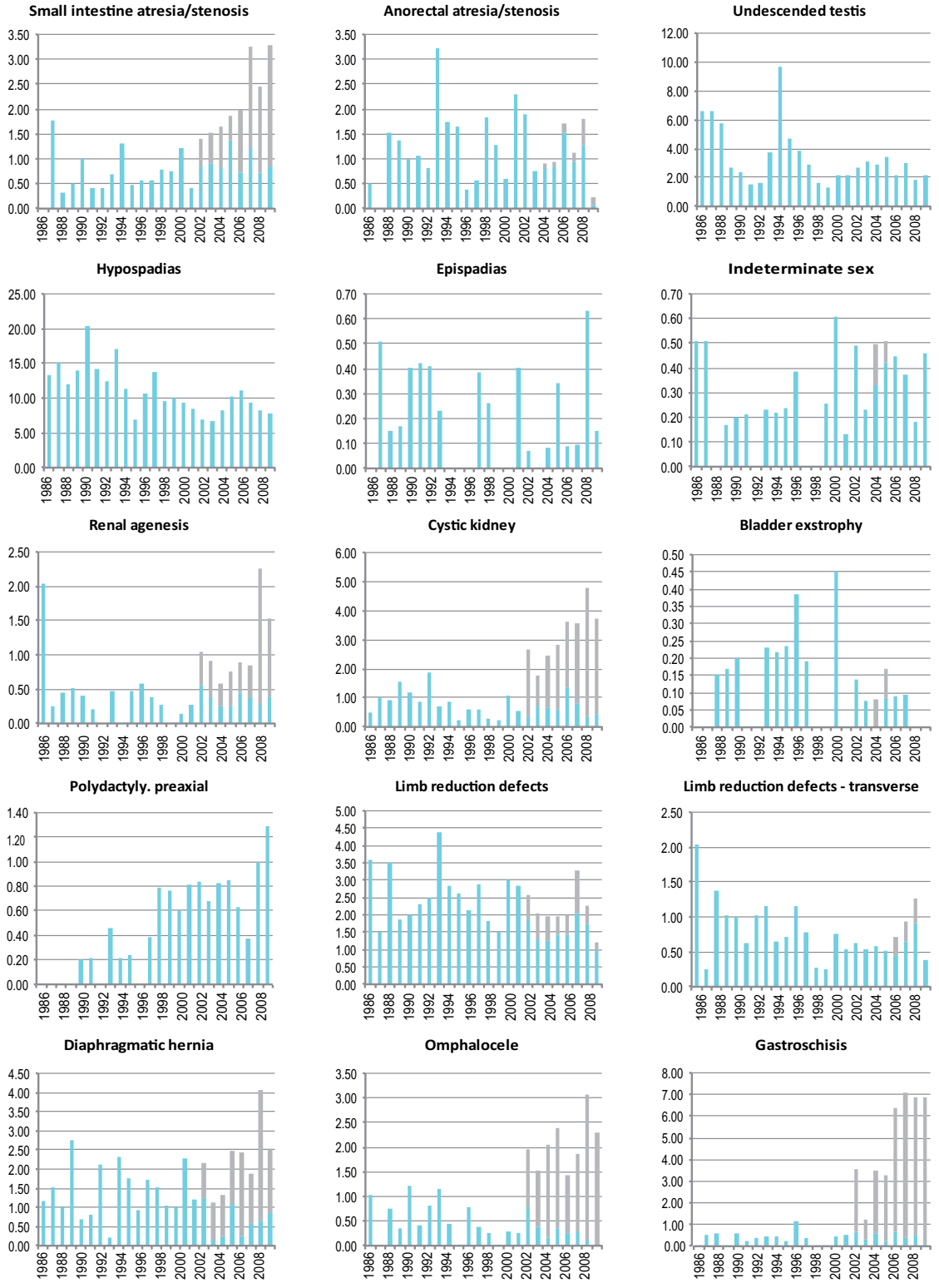
Cuba: RECUMAC

Time trends 1986-2009 (Birth prevalence rates per 10,000)



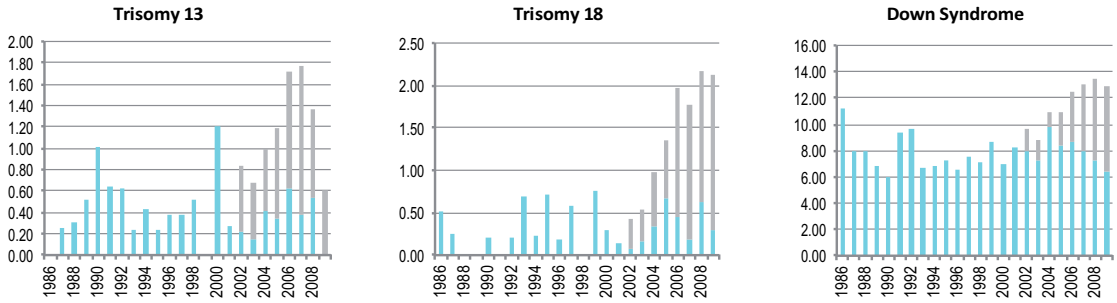
Note: L+S rates, ToP rates

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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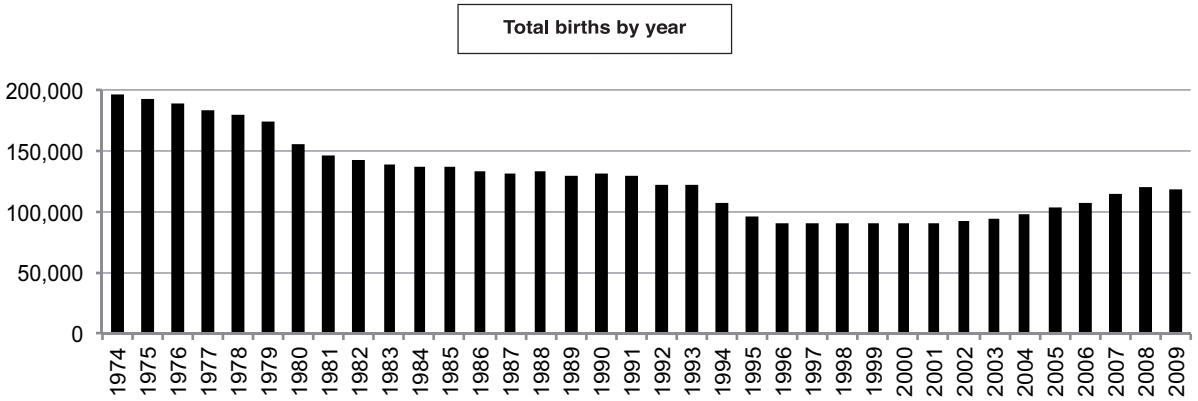
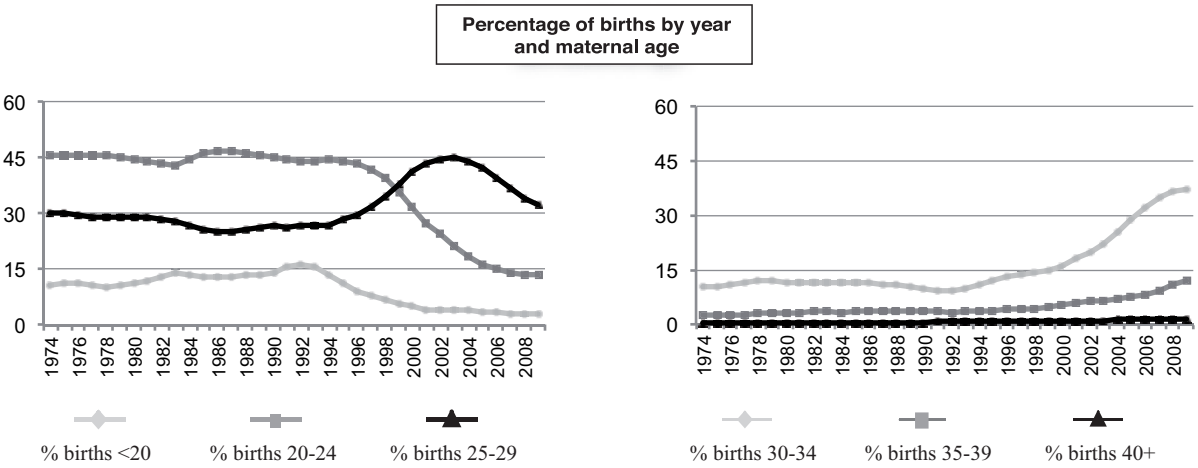
http://www.uzis.cz/

Czech Republic





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	89	96.7	Cystic kidney	42	16.1
Spina bifida	110	71.9	Limb reduction defects	47	17.9
Encephalocele	51	82.3	Diaphragmatic hernia	29	28.2
Holoprosencephaly	16	69.6	Omphalocele	68	63.0
Hydrocephaly	104	61.2	Gastroschisis	78	71.6
Hypoplastic left heart syndrome	72	64.3	Trisomy 13	57	86.4
Cleft palate without cleft lip	20	6.7	Trisomy 18	164	94.8
Cleft lip with or without cleft palate	55	12.9	Down syndrome	621	80.4
Renal agenesis	63	21.8			

Total ToPs with births defects = 2,615 (Ratio ToPs/Births: 7.40 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Czech Republic, 2009

Live births (LB)	118,348
Stillbirths (SB)	319
Total births	118,667
Number of terminations of pregnancy (ToP) for birth defects	911

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	29	2.44
Spina bifida	18	0	31	4.13
Encephalocele	5	0	14	1.60
Microcephaly	13	0	1	1.18
Holoprosencephaly	5	0	9	1.18
Hydrocephaly	17	1	29	3.96
Anophthalmos	2	0	nr	0.17
Microphthalmos	5	0	nr	0.42
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	3	0	nr	0.25
Microtia	6	0	nr	0.51
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	31	0	1	2.70
Tetralogy of Fallot	34	1	3	3.20
Hypoplastic left heart syndrome	9	0	19	2.36
Coarctation of aorta	42	0	5	3.96
Choanal atresia, bilateral	6	0	nr	0.51
Cleft palate without cleft lip	97	0	nr	8.17
Cleft lip with or without cleft palate	134	0	29	13.74
Oesophageal atresia/stenosis with or without fistula	45	0	nr	3.79
Small intestine atresia/stenosis	36	0	nr	3.03
Anorectal atresia/stenosis	68	0	nr	5.73
Undescended testis (36 weeks of gestation or later)	372	0	nr	31.35
Hypospadias	352	0	nr	29.66
Epispadias	4	0	nr	0.34
Indeterminate sex	7	1	nr	0.67
Renal agenesis	91	0	18	9.19
Cystic kidney	78	1	12	7.67
Bladder exstrophy	1	0	nr	0.08
Polydactyly, preaxial	193	1	nr	16.35
Total Limb reduction defects (include unspecified)	75	0	18	7.84
Transverse	26	0	nr	2.19
Preaxial	3	0	nr	0.25
Postaxial	4	0	nr	0.34
Intercalary	1	0	nr	0.08
Mixed	0	0	nr	0.00
Unspecified	41	0	nr	3.46
Diaphragmatic hernia	21	0	7	2.36
Omphalocele	10	0	18	2.36
Gastroschisis	13	0	25	3.20
Unspecified Omphalocele/Gastroschisis	4	0	nr	0.34
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	3	1	15	1.60
Trisomy 18	0	0	71	5.98
Down syndrome, all ages (include age unknown)	49	0	205	21.40
<20	0	0	0	0.00
20-24	4	0	15	11.87
25-29	10	0	24	8.89
30-34	15	0	60	17.06
35-39	13	0	69	57.33
40-44	7	0	34	215.34
45+	0	0	3	375.00
unknown	0	0	0	---

nr = not reported

Czech Republic, Previous years rates 1974 - 2009

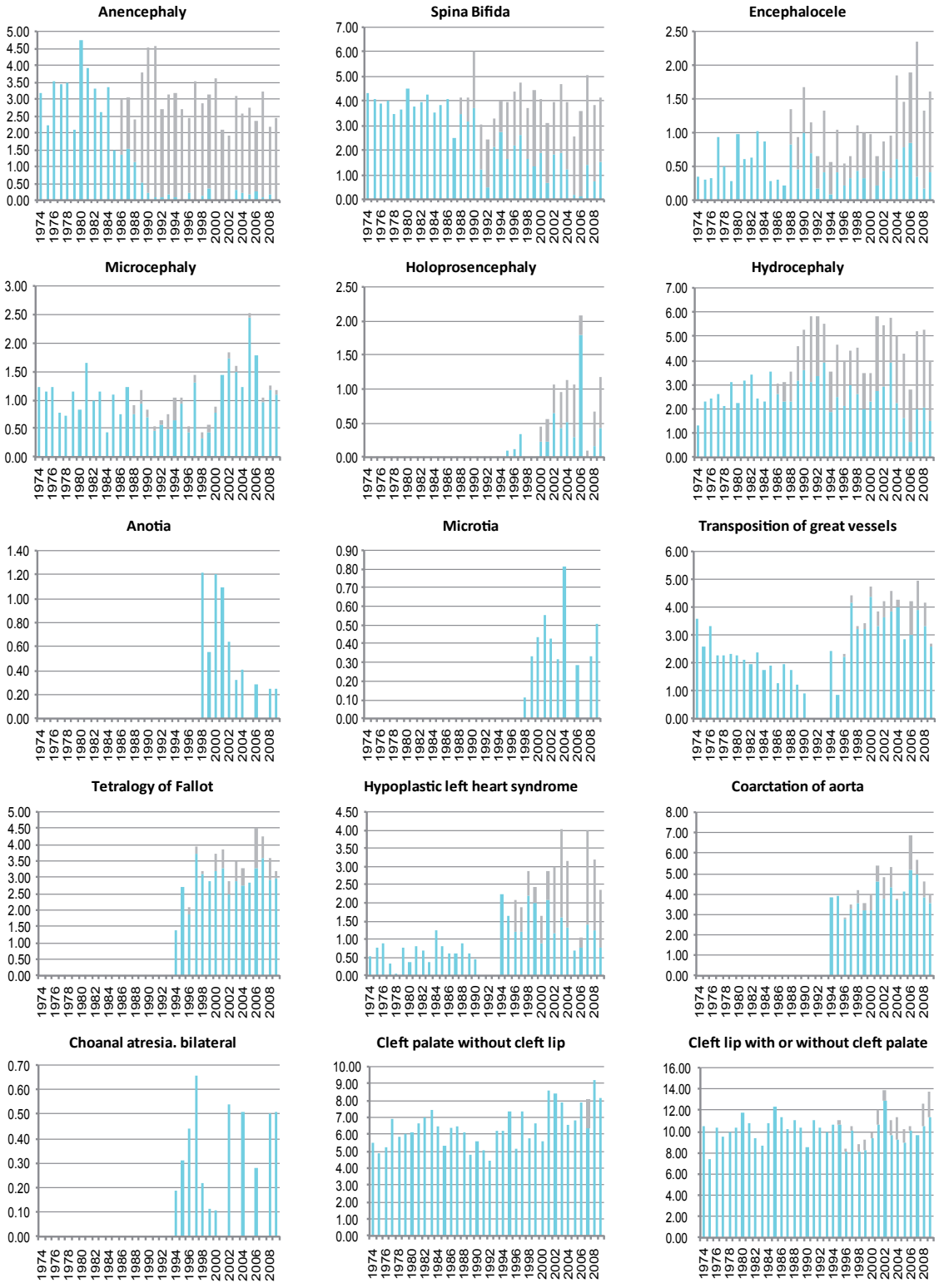
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**1,112,785**	**718,080**	**664,018**	**610,039**	**458,693**	**467,116**	**562,138**
Anencephaly	2.99	3.61	2.73	3.66	2.92	2.65	2.58
Spina bifida	3.91	4.02	3.73	3.79	4.25	3.96	3.86
Encephalocele	0.45	0.82	0.62	1.10	0.87	1.07	1.73
Microcephaly	1.04	1.02	1.02	0.75	0.81	1.39	1.53
Holoprosencephaly	nr	nr	nr	nr	0.11	0.83	1.00
Hydrocephaly	2.31	2.73	3.55	5.25	4.21	5.12	4.34
Anophthalmos	nr	nr	nr	nr	0.05*	0.04	0.41*
Microphthalmos	nr	nr	nr	nr	0.17*	0.30	0.43*
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	0.00*	0.00	0.20*
Anotia	nr	nr	nr	nr	0.89*	0.73	0.26*
Microtia	nr	nr	nr	nr	0.22*	0.51	0.38*
Unspecified Anotia/Microtia	nr	nr	nr	nr	4.76*	3.62	0.16
Transposition of great vessels	2.75	2.10	1.63	1.60*	2.83	4.32	3.79
Tetralogy of Fallot	nr	nr	nr	1.40*	2.96	3.45	3.68
Hypoplastic left heart syndrome	0.56	0.70	0.71	1.26*	2.18	2.95	2.31
Coarctation of aorta	nr	nr	nr	3.84*	3.62	4.65	5.02
Choanal atresia, bilateral	nr	nr	nr	0.19*	0.35	0.24	0.43*
Cleft palate without cleft lip	5.70	6.71	5.81	5.48	6.47	7.39	8.08
Cleft lip with or without cleft palate	9.66	10.29	11.05	10.06	9.61	11.65	11.42
Oesophageal atresia/stenosis with or without fistula	1.15	1.24	1.22	1.31	2.31	2.83	3.33
Small intestine atresia/stenosis	nr	nr	nr	1.78*	2.14	3.06	3.31
Anorectal atresia/stenosis	1.35	1.31	0.63	1.69	2.77	3.72	4.39
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	2.81*	10.03	23.55	30.23*
Hypospadias	18.30	19.89	22.73	23.44	25.94	31.28	31.47
Epispadias	nr	nr	nr	0.28*	0.50	0.39	0.35*
Indeterminate sex	nr	nr	nr	0.37*	0.44	0.49	0.41*
Renal agenesis	1.62	1.50	1.25	1.84	2.75	6.08	7.83
Cystic kidney	2.57	2.41	2.67	2.52	3.64	6.12	6.67
Bladder exstrophy	0.16	0.11	0.03	0.00*	0.17	0.21	0.06*
Polydactyly, preaxial	nr	nr	13.09*	12.21	13.06	14.19	14.93
Total Limb reduction defects (include unspecified)	4.34	5.07	4.61	5.66	4.82	6.14	6.80
Transverse	nr	nr	nr	nr	nr	nr	1.89*
Preaxial	nr	nr	nr	nr	nr	nr	0.25*
Postaxial	nr	nr	nr	nr	nr	nr	0.17*
Intercalary	nr	nr	nr	nr	nr	nr	0.08*
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	3.40*
Diaphragmatic hernia	2.62	2.52	2.27	1.57	2.53	2.83	2.65
Omphalocele	2.32	2.14	2.56	2.03	2.55	2.74	2.69
Gastroschisis	1.02	1.38	1.17	0.62	3.14	2.85	3.10
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.00	0.02	0.00	0.09*
Prune belly sequence	nr	nr	nr	nr	nr	0.16*	0.04*
Trisomy 13	nr	nr	nr	0.33	0.92	1.80	1.97
Trisomy 18	nr	nr	0.42*	1.13	3.03	4.13	5.12
Down syndrome, all ages (include age unknown)	8.35	8.15	8.25	10.74	14.32	16.78	21.03
<20	4.84	4.49	4.68	4.69	7.79	6.11	3.83
20-24	5.46	4.83	3.85	4.21	8.44	7.67	9.69
25-29	8.38	7.50	6.95	7.06	10.16	10.65	9.81
30-34	11.81	9.67	7.91	12.08	17.76	19.93	18.59
35-39	32.61	31.38	27.37	40.58	58.39	61.66	63.37
40-44	123.51	99.30	68.99	195.32	204.38	185.31	211.51
45+	207.47	360.36	404.04	608.70	454.55	635.84	529.80
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

Czech Republic

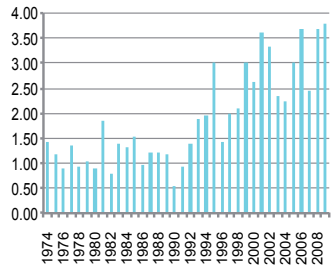
Time trends 1974-2009 (Birth prevalence rates per 10,000)



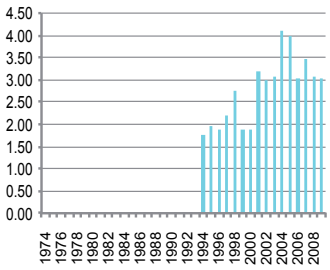
Note: L+S rates, ToP rates

Czech Republic

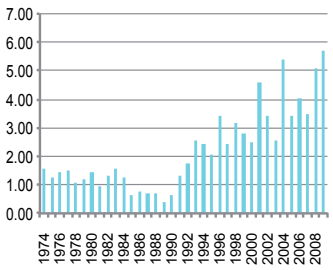
Oesophageal atresia/stenosis with or without fistula



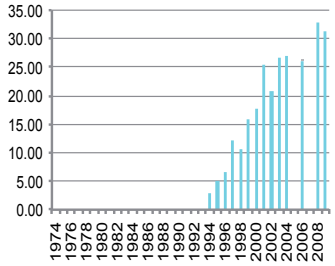
Small intestine atresia/stenosis



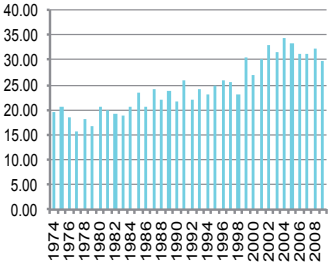
Anorectal atresia/stenosis



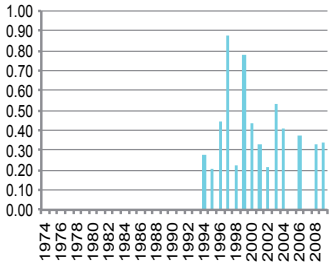
Undescended testis



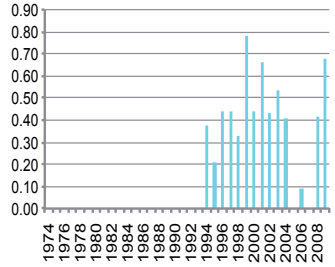
Hypospadias



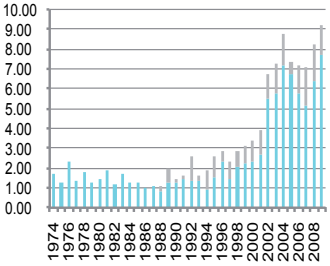
Epispadias



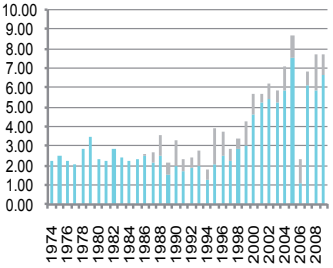
Indeterminate sex



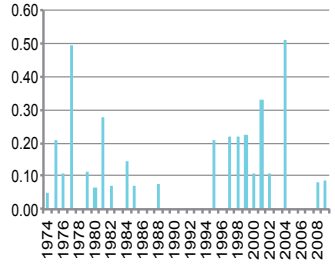
Renal agenesis



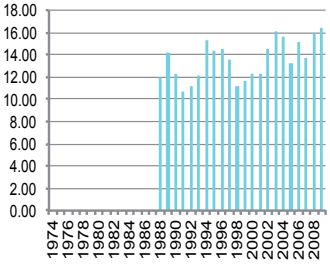
Cystic kidney



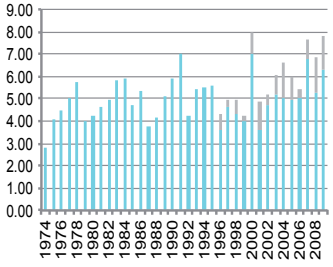
Bladder exstrophy



Polydactyly, preaxial



Limb reduction defects



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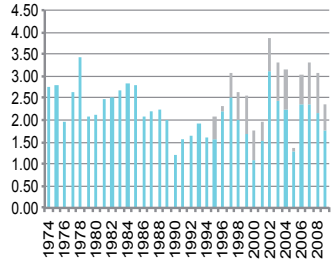
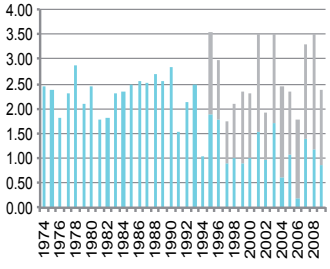
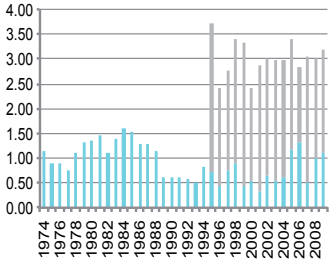


Omphalocele



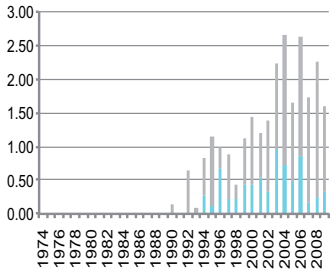
Gastroschisis



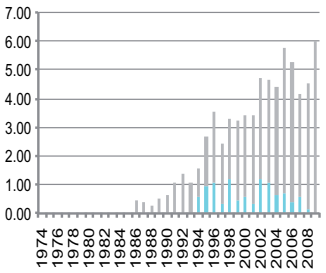
Note: L+S rates, ToP rates

Czech Republic

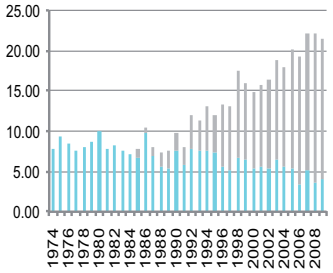
Trisomy 13



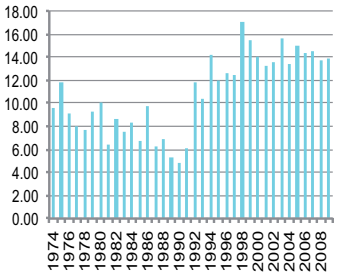
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Finland
The Finnish Register of Congenital Malformations

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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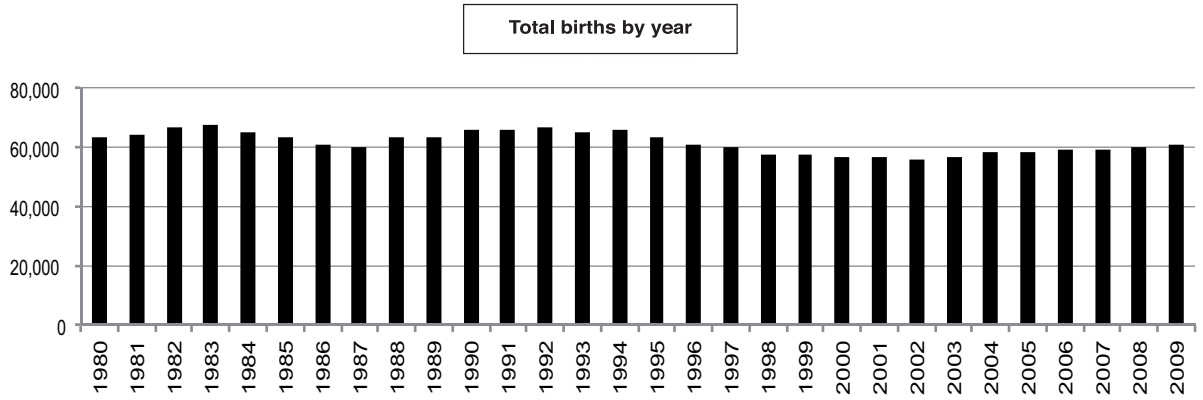
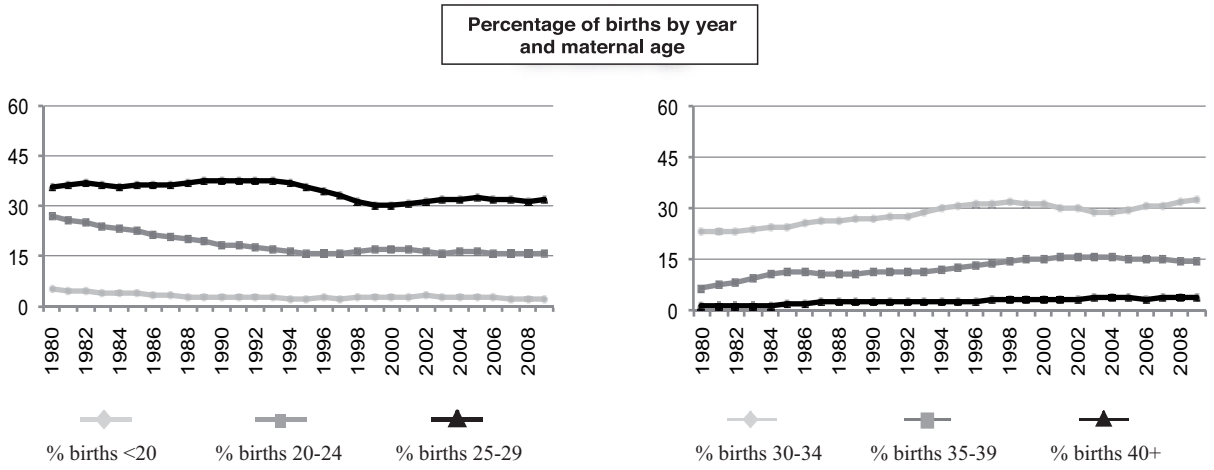
E-mail: annukka.ritvanen(at)thl.fi
Website: http://www.thl.fi or http://www.thl.fi/statistics/congenitalmalformations

Finland





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	55	88.7	Cystic kidney	44	25.4
Spina bifida	46	54.1	Limb reduction defects	31	23.1
Encephalocele	30	83.3	Diaphragmatic hernia	23	38.3
Holoprosencephaly	29	78.4	Omphalocele	61	70.9
Hydrocephaly	40	47.6	Gastroschisis	12	23.1
Hypoplastic left heart syndrome	34	48.6	Trisomy 13	43	81.1
Cleft palate without cleft lip	18	7.3	Trisomy 18	94	79.7
Cleft lip with or without cleft palate	36	17.2	Down syndrome	308	55.9
Renal agenesis	9	42.9			

Total ToPs with births defects = 967 (Ratio ToPs/Births: 5.39 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Finland, 2009

Live births (LB)	60,430
Stillbirths (SB)	205
Total births	60,635
Number of terminations of pregnancy (ToP) for birth defects	353

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	2	18	3.46
Spina bifida	14	0	14	4.62
Encephalocele	1	0	6	1.15
Microcephaly	15	0	4	3.13
Holoprosencephaly	2	1	8	1.81
Hydrocephaly	12	0	16	4.62
Anophthalmos	0	0	1	0.16
Microphthalmos	4	0	2	0.99
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	20	0	0	3.30
Transposition of great vessels	18	1	7	4.29
Tetralogy of Fallot	16	0	4	3.30
Hypoplastic left heart syndrome	18	0	22	6.60
Coarctation of aorta	56	0	2	9.57
Choanal atresia, bilateral	2	1	1	0.66
Cleft palate without cleft lip	86	2	7	15.67
Cleft lip with or without cleft palate	54	1	11	10.88
Oesophageal atresia/stenosis with or without fistula	25	3	1	4.78
Small intestine atresia/stenosis	2	0	0	0.33
Anorectal atresia/stenosis	19	0	2	3.46
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	31	0	0	5.11
Epispadias	0	0	0	0.00
Indeterminate sex	7	0	2	1.48
Renal agenesis	4	1	5	1.65
Cystic kidney	42	0	19	10.06
Bladder exstrophy	2	0	1	0.49
Polydactyly, preaxial	34	0	1	5.77
Total Limb reduction defects (include unspecified)	33	1	15	8.08
Transverse	21	1	7	4.78
Preaxial	6	0	5	1.81
Postaxial	0	0	0	0.00
Intercalary	2	0	1	0.49
Mixed	1	0	0	0.16
Unspecified	3	0	2	0.82
Diaphragmatic hernia	10	0	5	2.47
Omphalocele	7	0	20	4.45
Gastroschisis	14	1	3	2.97
Unspecified Omphalocele/Gastroschisis	0	0	2	0.33
Prune belly sequence	1	0	1	0.33
Trisomy 13	4	1	16	3.46
Trisomy 18	8	1	34	7.09
Down syndrome, all ages (include age unknown)	75	3	110	31.01
<20	0	0	1	7.15
20-24	8	0	1	9.52
25-29	8	0	12	10.34
30-34	17	1	23	20.93
35-39	28	0	33	70.75
40-44	11	2	37	232.67
45+	3	0	3	722.89
unknown	0	0	0	---

nr = not reported

Finland, Previous years rates 1993 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994*	1995-1999	2000-2004	2005-2009
Total births				**130,578**	**299,029**	**283,887**	**296,247**
Anencephaly				2.14	3.21	2.96	3.24
Spina bifida				4.06	4.88	4.33	4.73
Encephalocele				1.30	1.27	1.97	1.79
Microcephaly				2.53	2.31	1.73	2.70
Holoprosencephaly				1.30	1.40	1.41	1.92
Hydrocephaly				8.73	6.52	5.57	4.79
Anophthalmos				0.54	0.43	0.63	0.41
Microphthalmos				1.99	1.64	1.62	0.78
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.00	0.00
Anotia				nr	nr	nr	nr
Microtia				nr	nr	nr	nr
Unspecified Anotia/Microtia				5.21	4.68	4.09	4.15
Transposition of great vessels				4.06	4.15	3.91	3.92
Tetralogy of Fallot				2.07	3.61	3.84	3.98
Hypoplastic left heart syndrome				3.14	3.68	4.19	3.88
Coarctation of aorta				7.73	9.93	10.39	9.18
Choanal atresia, bilateral				0.77	0.94	0.95	0.81
Cleft palate without cleft lip				17.69	13.38	13.67	14.14
Cleft lip with or without cleft palate				10.64	10.87	11.27	11.51
Oesophageal atresia/stenosis with or without fistula				3.06	3.75	3.87	4.05
Small intestine atresia/stenosis				1.23	1.04	1.16	0.98
Anorectal atresia/stenosis				5.90	4.98	5.00	5.20
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				3.60	3.31	3.42	4.22
Epispadias				0.23	0.23	0.39	0.34
Indeterminate sex				0.84	1.04	1.90	1.55
Renal agenesis				1.99	1.74	1.44	1.32
Cystic kidney				6.51	6.05	7.82	9.28
Bladder exstrophy				0.54	0.47	0.70	0.71
Polydactyly, preaxial				4.82	4.28	4.19	5.20
Total Limb reduction defects (include unspecified)				7.73	6.86	7.75	7.02
Transverse				4.67	3.81	3.84	4.12
Preaxial				1.76	1.74	2.61	1.32
Postaxial				0.31	0.37	0.46	0.47
Intercalary				0.31	0.50	0.28	0.37
Mixed				0.54	0.37	0.18	0.27
Unspecified				0.08	0.07	0.00	0.47
Diaphragmatic hernia				2.53	2.61	2.75	3.44
Omphalocele				3.98	4.01	5.00	5.33
Gastroschisis				1.76	2.31	3.31	3.17
Unspecified Omphalocele/Gastroschisis				0.23	0.23	0.35	0.54
Prune belly sequence				0.31	0.27	0.25	0.24
Trisomy 13				2.14	2.14	2.11	2.60
Trisomy 18				4.98	5.79	6.73	6.78
Down syndrome, all ages (include age unknown)				23.20	22.61	25.89	29.94
<20				21.35	9.14	7.10	9.46
20-24				6.46	7.04	7.43	9.93
25-29				11.50	10.09	11.24	12.25
30-34				19.03	17.48	15.91	22.51
35-39				61.46	52.43	58.17	62.33
40-44				163.30	170.83	188.20	204.71
45+				459.77	209.64	401.53	466.53
unknown				---	---	---	---

nr = not reported
* data include less than 5 years

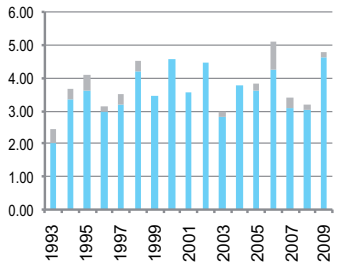
Finland

Time trends 1993-2009 (Birth prevalence rates per 10,000)

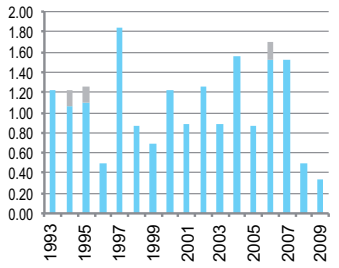
Note: L+S rates, ToP rates

Finland

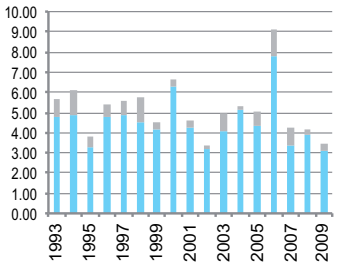
Oesophageal atresia/stenosis with or without fistula



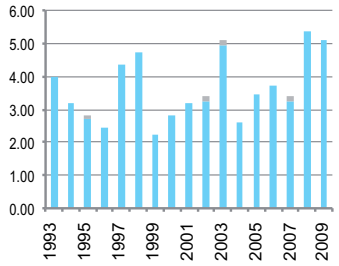
Small intestine atresia/stenosis



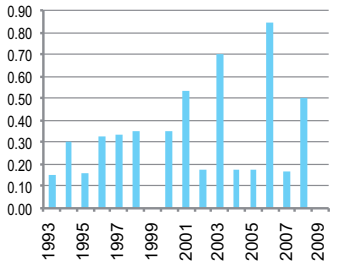
Anorectal atresia/stenosis



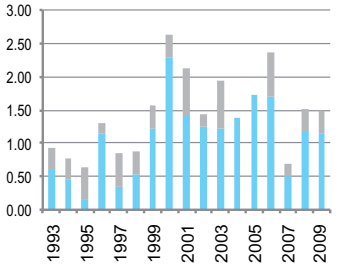
Hypospadias



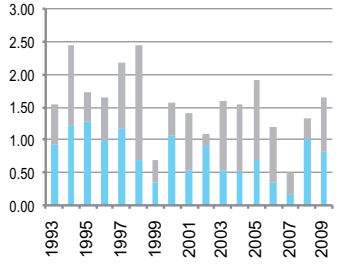
Epispadias



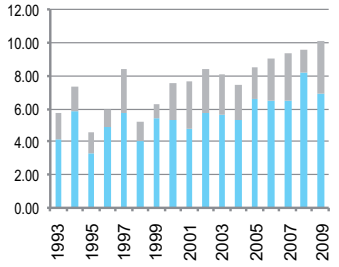
Indeterminate sex



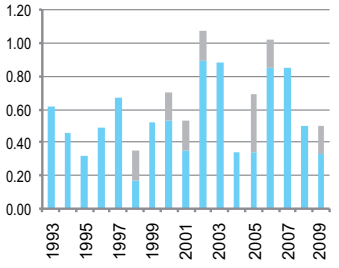
Renal agenesis



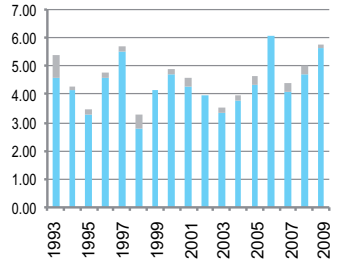
Cystic kidney



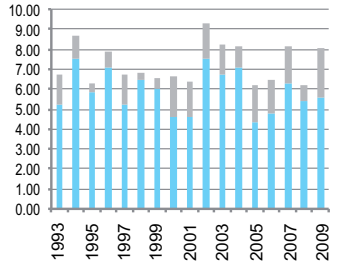
Bladder exstrophy



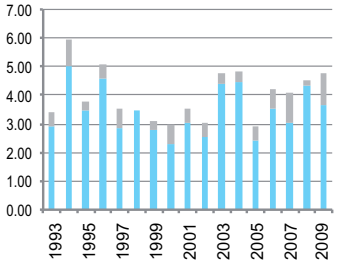
Polydactyly, preaxial



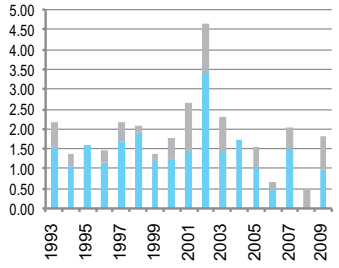
Limb reduction defects



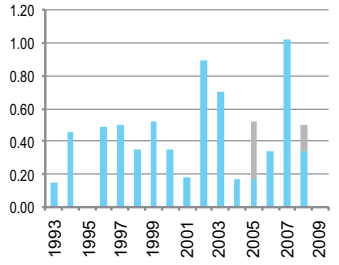
Limb reduction defects - transverse



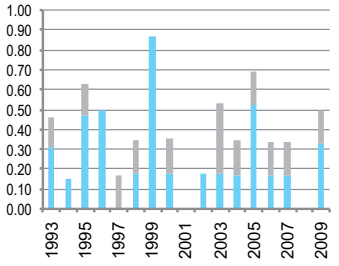
Limb reduction defects - preaxial



Limb reduction defects - postaxial

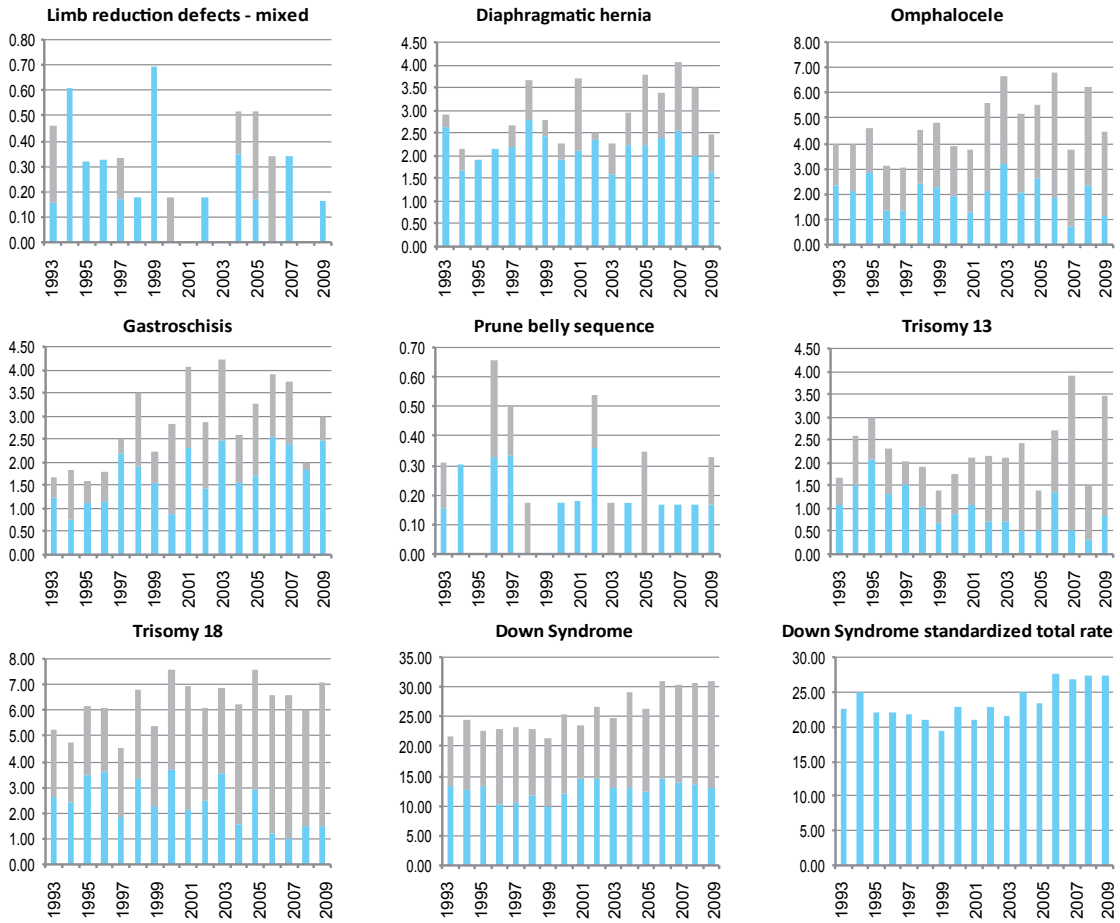


Limb reduction defects - intercalary



Note: L+S rates, ToP rates

Finland



Note: L+S rates, ToP rates

France: Paris

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

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

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

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

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

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

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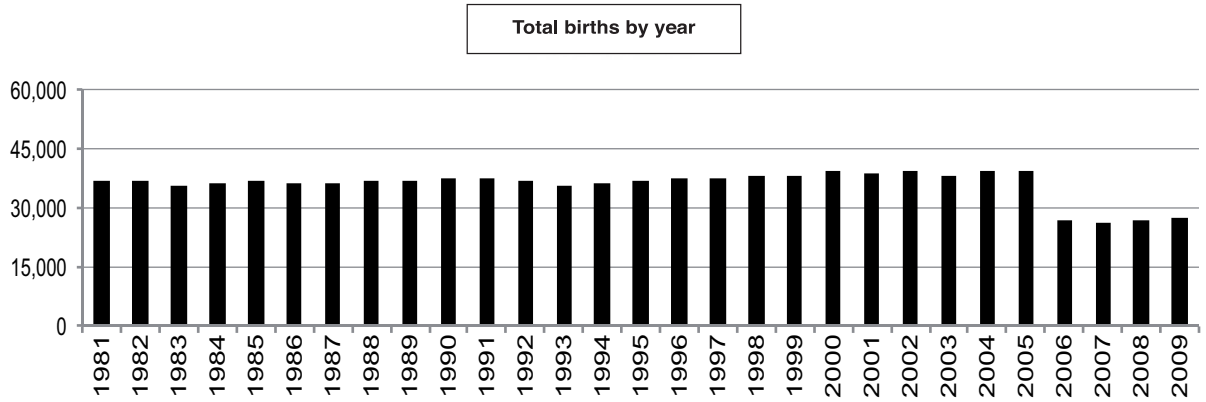
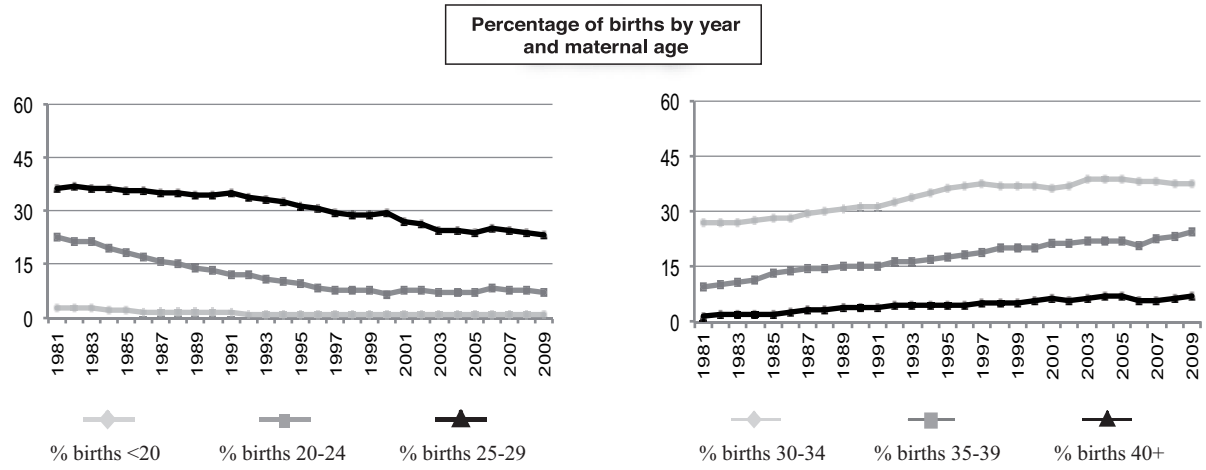
France: Paris





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	40	97.6	Cystic kidney	18	21.7
Spina bifida	42	91.3	Limb reduction defects	22	43.1
Encephalocele	12	66.7	Diaphragmatic hernia	6	28.6
Holoprosencephaly	21	91.3	Omphalocele	39	78.0
Hydrocephaly	48	35.0	Gastroschisis	2	15.4
Hypoplastic left heart syndrome	15	55.6	Trisomy 13	38	95.0
Cleft palate without cleft lip	8	14.5	Trisomy 18	113	91.1
Cleft lip with or without cleft palate	22	30.6	Down syndrome	257	76.5
Renal agenesis	10	100.0			

Total ToPs with births defects = 831 (Ratio ToPs/Births: 10.38 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Paris, 2009

Live births (LB)	26,754
Stillbirths (SB)	426
Total births	27,180
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	0	15	5.52
Spina bifida	1	0	17	6.62
Encephalocele	1	0	1	0.74
Microcephaly	3	0	4	2.58
Holoprosencephaly	1	0	5	2.21
Hydrocephaly	30	0	13	15.82
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	1	0.74
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	4	0	0	1.47
Microtia	0	0	1	0.37
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	9	0	1	3.68
Tetralogy of Fallot	5	0	1	2.21
Hypoplastic left heart syndrome	3	0	6	3.31
Coarctation of aorta	10	0	3	4.78
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	13	0	2	5.52
Cleft lip with or without cleft palate	19	0	6	9.20
Oesophageal atresia/stenosis with or without fistula	6	0	1	2.58
Small intestine atresia/stenosis	4	0	0	1.47
Anorectal atresia/stenosis	5	0	5	3.68
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	44	0	0	16.19
Epispadias	2	0	0	0.74
Indeterminate sex	3	0	0	1.10
Renal agenesis	0	0	0	0.00
Cystic kidney	26	0	4	11.04
Bladder exstrophy	4	0	3	2.58
Polydactyly, preaxial	2	0	0	0.74
Total Limb reduction defects (include unspecified)	9	0	7	5.89
Transverse	6	0	5	4.05
Preaxial	1	0	0	0.37
Postaxial	1	0	0	0.37
Intercalary	1	0	0	0.37
Mixed	0	0	0	0.00
Unspecified	0	0	2	0.74
Diaphragmatic hernia	7	0	1	2.94
Omphalocele	3	0	15	6.62
Gastroschisis	5	0	2	2.58
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	13	4.78
Trisomy 18	2	2	38	15.45
Down syndrome, all ages (include age unknown)	30	1	83	41.94
<20	0	0	0	0.00
20-24	2	0	1	15.89
25-29	5	0	9	22.22
30-34	8	0	17	24.51
35-39	11	0	29	60.05
40-44	2	1	25	165.39
45+	1	0	2	181.82
unknown	1	0	0	---

nr = not reported

France: Paris, Previous years rates 1981 - 2009

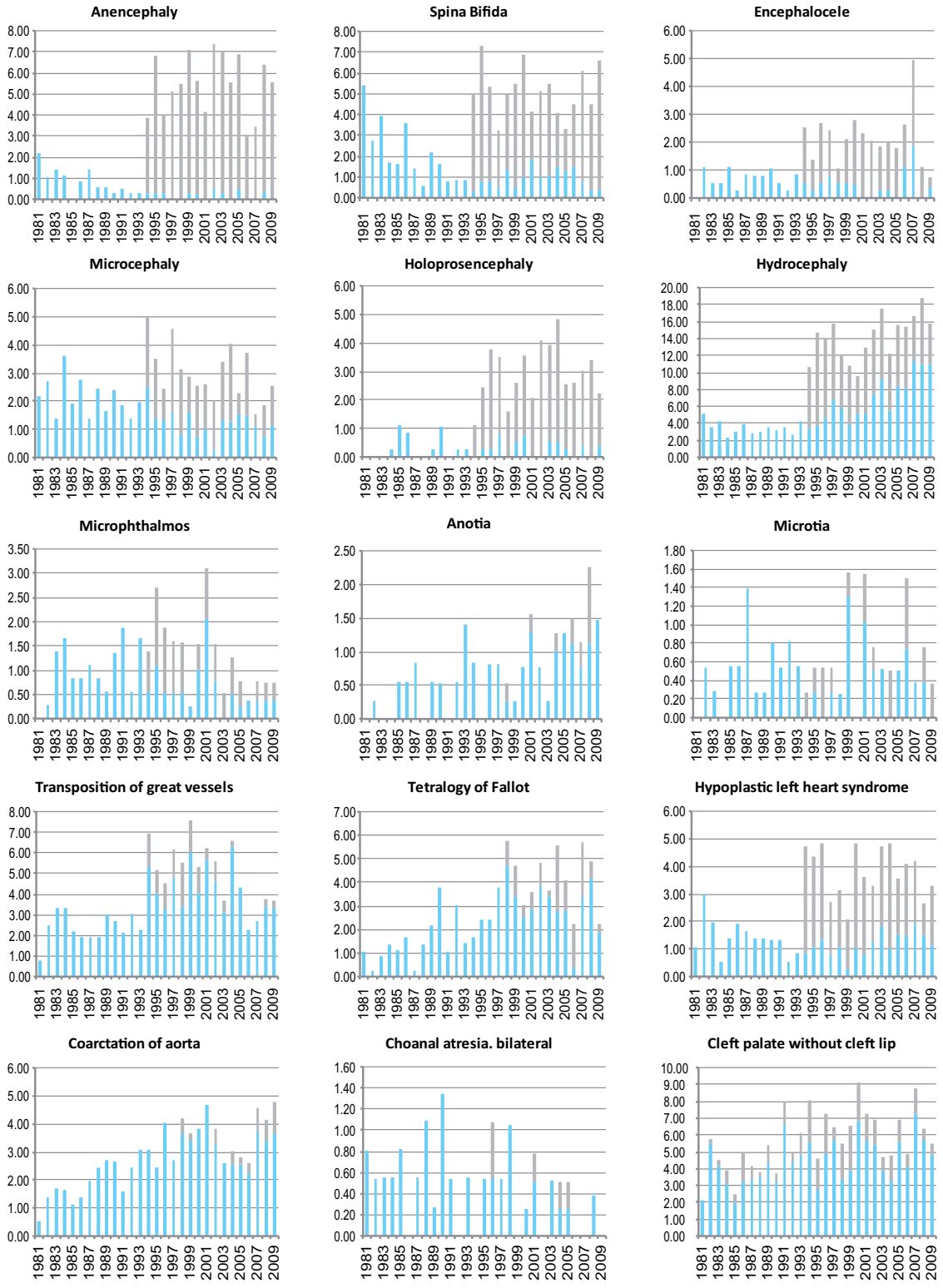
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984*	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**145,343**	**182,538**	**183,049**	**187,753**	**195,150**	**146,147**	
Anencephaly	1.44	0.66	1.04	5.70	5.94	5.20	
Spina bifida	3.44	1.86	1.80	5.27	5.12	4.86	
Encephalocele	0.55	0.77	1.04	1.92	2.20	2.19	
Microcephaly	2.48	2.03	2.51	3.30	2.92	2.39	
Holoprosencephaly	0.07	0.44	0.55	2.77	3.69	2.74	
Hydrocephaly	3.78	3.23	4.81	13.42	13.43	16.35	
Anophthalmos	0.34	0.00	0.55	0.16	0.31	0.21	
Microphthalmos	0.83	0.82	1.37	1.60	1.59	0.68	
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	0.07	0.49	0.66	0.48	0.92	1.51	
Microtia	0.21	0.60	0.60	0.69	0.67	0.68	
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	2.48	2.19	3.39	5.81	5.48	3.42	
Tetralogy of Fallot	0.89	1.31	2.19	3.83	4.15	3.83	
Hypoplastic left heart syndrome	1.65	1.53	1.75	3.41	4.25	3.56	
Coarctation of aorta	1.31	1.92	2.57	3.41	3.59	3.69	
Choanal atresia, bilateral	0.62	0.55	0.49	0.64	0.41	0.21	
Cleft palate without cleft lip	4.06	4.16	6.17	6.07	6.56	6.50	
Cleft lip with or without cleft palate	6.67	7.29	9.67	9.11	7.89	9.17	
Oesophageal atresia/stenosis with or without fistula	2.27	2.79	3.33	3.94	4.36	3.28	
Small intestine atresia/stenosis	0.41	0.99	1.69	2.29	3.48	2.94	
Anorectal atresia/stenosis	3.51	1.75	3.39	3.25	4.05	2.87	
Undescended testis (36 weeks of gestation or later)	8.53	13.37	11.09	6.50	6.39*	nr	
Hypospadias	10.46	10.52	15.46	10.28	14.86	14.92	
Epispadias	0.07	0.60	0.55	0.37	0.31	0.75	
Indeterminate sex	1.58	1.15	1.42	1.23	1.23	1.37	
Renal agenesis	1.03	1.04	1.20	3.41	2.36	2.39	
Cystic kidney	1.58	3.07	5.30	9.05	10.86	10.06	
Bladder exstrophy	0.21	0.33	0.60	0.69	0.36	0.96	
Polydactyly, preaxial	0.62	0.82	1.69	2.45	1.43	1.57	
Total Limb reduction defects (include unspecified)	nr	nr	nr	6.60	8.51	5.82	
Transverse	nr	nr	nr	2.93	4.56	3.56	
Preaxial	nr	nr	nr	0.85	1.43	1.16	
Postaxial	nr	nr	nr	0.27	0.97	0.27	
Intercalary	nr	nr	nr	0.48	0.46	0.34	
Mixed	nr	nr	nr	0.27	0.77	0.21	
Unspecified	nr	nr	nr	0.05	0.31	0.27	
Diaphragmatic hernia	2.00	3.18	3.11	5.59	5.38	3.56	
Omphalocele	1.58	1.81	2.08	5.01	6.35	5.75	
Gastroschisis	0.48	0.82	1.97	2.56	3.69	1.71	
Unspecified Omphalocele/Gastroschisis	0.28	0.49	0.38	0.80	1.08	0.75	
Prune belly sequence	0.07	0.16	0.00	0.16	0.15	0.14	
Trisomy 13	0.41	0.55	0.87	3.52	4.56	4.52	
Trisomy 18	1.65	0.93	2.51	8.10	12.55	14.23	
Down syndrome, all ages (include age unknown)	11.49	12.65	17.48	34.46	38.79	43.93	
<20	10.09	15.83	4.51	5.95	24.05	0.00	
20-24	6.80	5.79	9.76	14.61	11.10	9.05	
25-29	6.79	6.36	8.68	14.20	13.55	17.57	
30-34	11.19	12.99	13.52	21.40	21.55	24.92	
35-39	24.04	30.13	31.42	56.98	60.55	64.83	
40-44	57.41	25.54	83.26	199.31	188.13	219.89	
45+	220.99	158.10	161.73	334.93	400.57	283.29	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

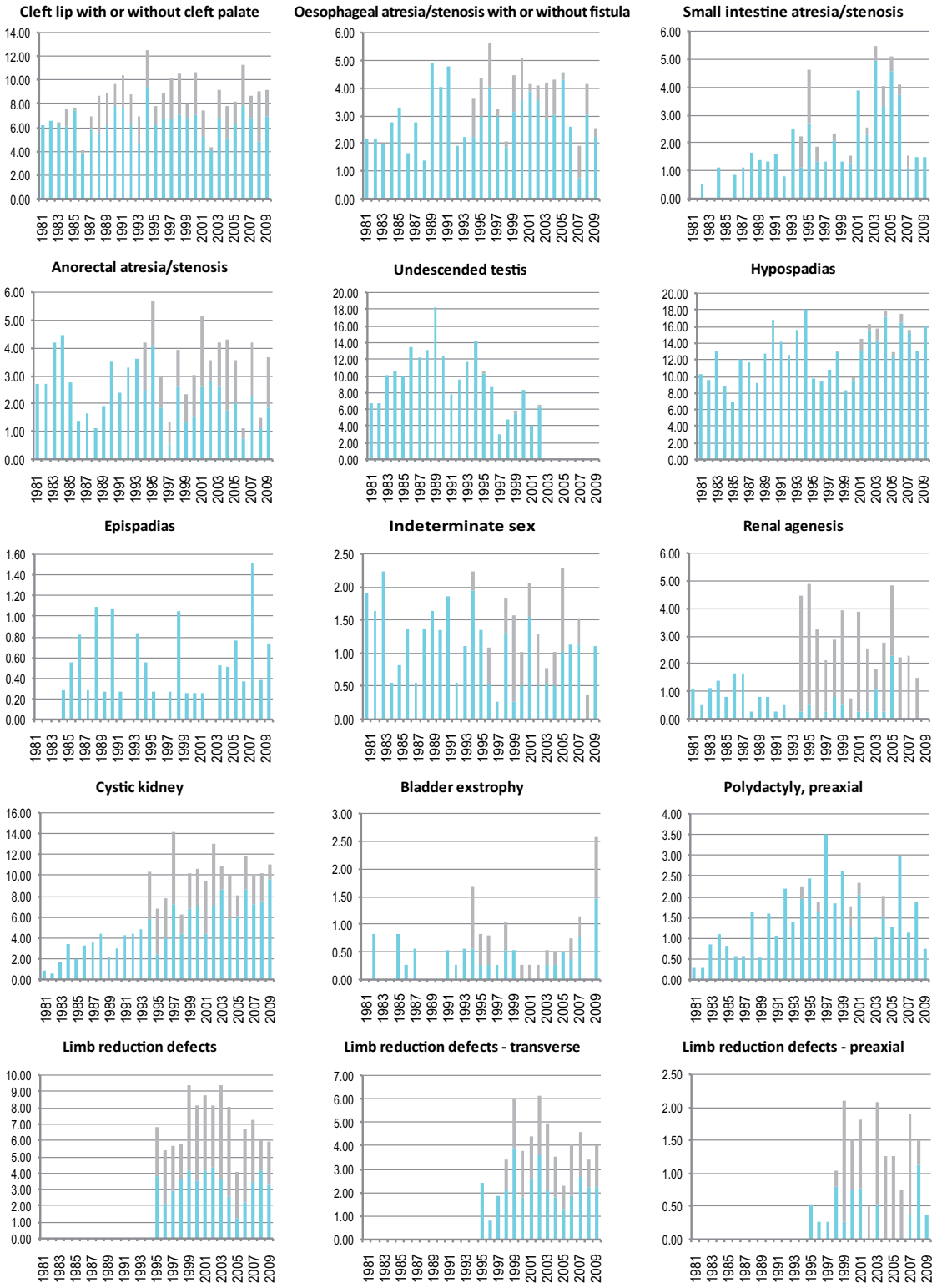
France: Paris

Time trends 1981-2009 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

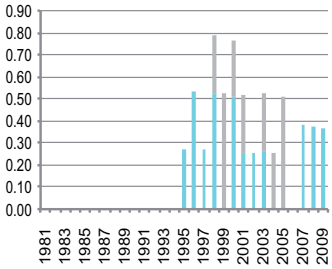
France: Paris



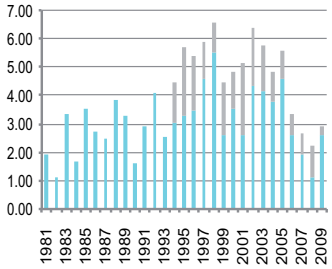
Note: L+S rates, ToP rates

France: Paris

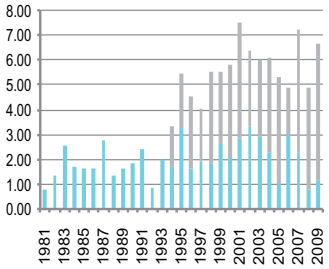
Limb reduction defects - intercalary



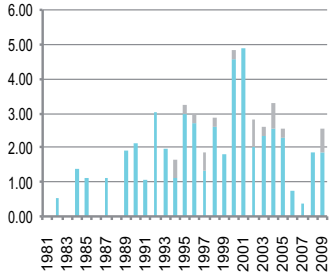
Diaphragmatic hernia



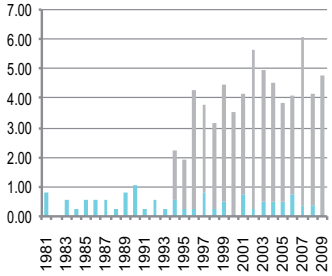
Omphalocele



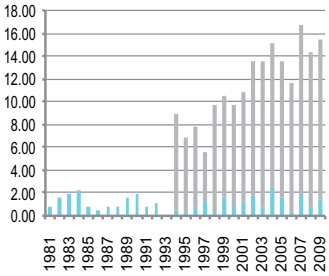
Gastroschisis



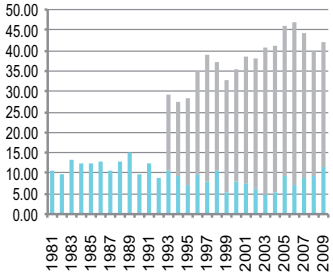
Trisomy 13



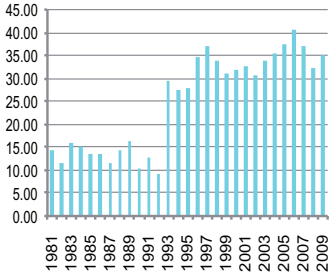
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

France: REMERA

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

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

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

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

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

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

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

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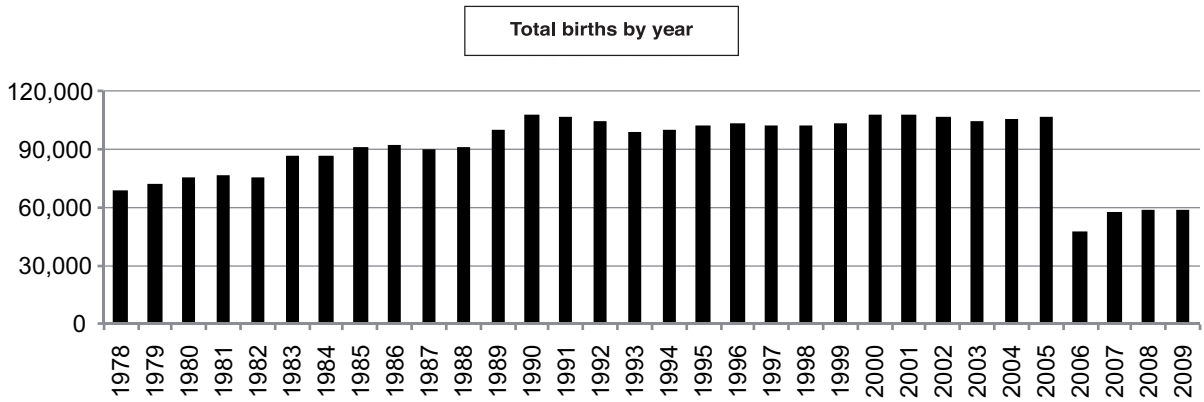
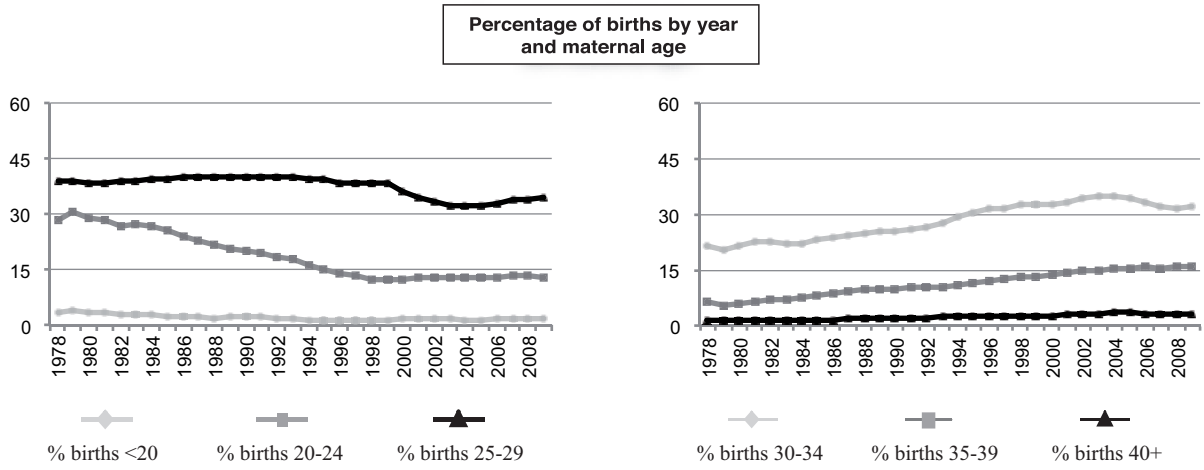
France: REMERA





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	70	94.6	Cystic kidney	63	42.3
Spina bifida	87	85.3	Limb reduction defects	46	46.5
Encephalocele	22	84.6	Diaphragmatic hernia	17	28.8
Holoprosencephaly	36	92.3	Omphalocele	46	68.7
Hydrocephaly	92	63.9	Gastroschisis	6	14.0
Hypoplastic left heart syndrome	51	58.6	Trisomy 13	43	91.5
Cleft palate without cleft lip	22	23.7	Trisomy 18	120	95.2
Cleft lip with or without cleft palate	49	27.5	Down syndrome	384	81.9
Renal agenesis	29	32.6			

Total ToPs with births defects = 1,348 (Ratio ToPs/Births: 7,67 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: REMERA, 2009

Live births (LB)	58,368
Stillbirths (SB)	701
Total births	59,069
Number of terminations of pregnancy (ToP) for birth defects	487

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	27	4.57
Spina bifida	2	0	34	6.09
Encephalocele	0	1	10	1.86
Microcephaly	2	1	6	1.52
Holoprosencephaly	1	0	11	2.03
Hydrocephaly	9	5	30	7.45
Anophthalmos	0	0	2	0.34
Microphthalmos	1	1	2	0.68
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	2	1	0.68
Microtia	0	2	2	0.68
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	21	1	9	5.25
Tetralogy of Fallot	15	0	4	3.22
Hypoplastic left heart syndrome	7	2	14	3.89
Coarctation of aorta	11	1	2	2.37
Choanal atresia, bilateral	2	0	0	0.34
Cleft palate without cleft lip	24	0	8	5.42
Cleft lip with or without cleft palate	48	3	17	11.51
Oesophageal atresia/stenosis with or without fistula	23	1	3	4.57
Small intestine atresia/stenosis	10	0	1	1.86
Anorectal atresia/stenosis	1	0	0	0.17
Undescended testis (36 weeks of gestation or later)	7	0	1	1.35
Hypospadias	53	0	5	9.82
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	2	0.51
Renal agenesis	20	0	11	5.25
Cystic kidney	31	4	22	9.65
Bladder exstrophy	1	0	2	0.51
Polydactyly, preaxial	51	0	8	9.99
Total Limb reduction defects (include unspecified)	13	1	18	5.42
Transverse	6	0	9	2.54
Preaxial	5	0	6	1.86
Postaxial	2	0	2	0.68
Intercalary	0	1	0	0.17
Mixed	0	0	1	0.17
Unspecified	0	0	0	0.00
Diaphragmatic hernia	12	2	6	3.39
Omphalocele	7	2	19	4.74
Gastroschisis	18	0	2	3.39
Unspecified Omphalocele/Gastroschisis	1	0	5	1.02
Prune belly sequence	1	0	0	0.17
Trisomy 13	2	0	9	1.86
Trisomy 18	0	0	38	6.43
Down syndrome, all ages (include age unknown)	19	1	141	27.26
<20	0	0	0	0.00
20-24	0	0	5	6.53
25-29	4	1	13	8.85
30-34	6	0	35	21.75
35-39	4	0	49	57.11
40-44	2	0	34	191.90
45+	0	0	4	408.16
unknown	3	0	1	---

France: REMERA, Previous years rates 1978 - 2009

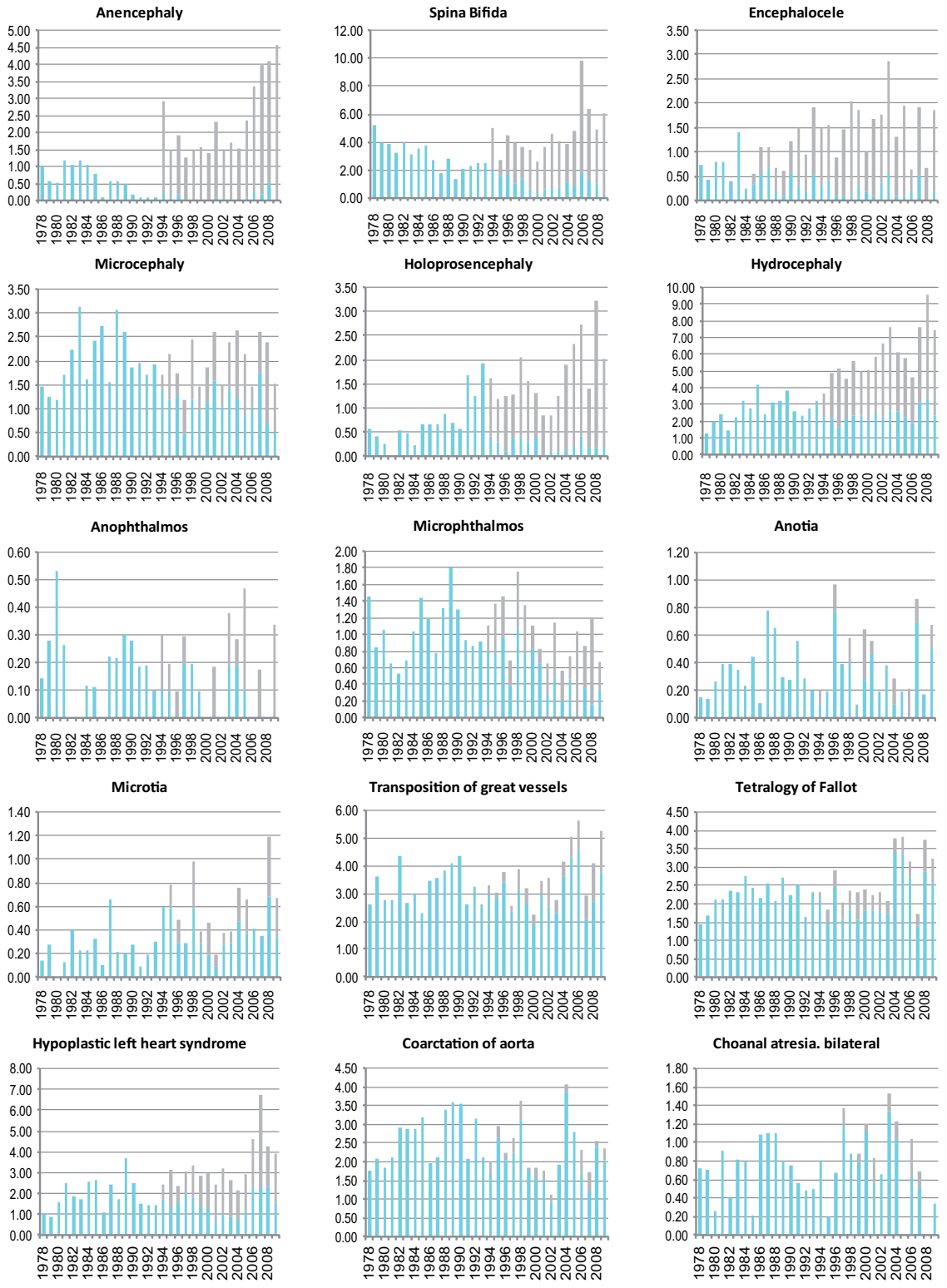
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979*	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**140,274**	**400,702**	**464,127**	**517,380**	**513,148**	**533,361**	**330,525**
Anencephaly	0.78	1.00	0.50	0.66	1.54	1.69	3.48
Spina bifida	4.56	3.54	2.48	2.84	3.66	3.75	6.05
Encephalocele	0.57	0.72	0.80	1.41	1.56	1.72	1.51
Microcephaly	1.35	2.00	2.48	1.84	1.79	2.19	2.06
Holoprosencephaly	0.50	0.30	0.71	1.39	1.46	1.22	2.33
Hydrocephaly	1.64	2.45	3.34	2.90	5.01	6.26	6.90
Anophthalmos	0.21	0.17	0.17	0.21	0.18	0.17	0.24
Microphthalmos	1.14	0.80	1.31	1.02	1.33	0.86	0.88
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.21
Anotia	0.14	0.32	0.45	0.31	0.45	0.41	0.39
Microtia	0.21	0.20	0.30	0.29	0.58	0.43	0.67
Unspecified Anotia/Microtia	0.36	0.52	0.75	0.44	1.03	0.49	0.21
Transposition of great vessels	3.14	3.09	3.47	3.25	3.29	3.22	4.63
Tetralogy of Fallot	1.57	2.35	2.39	2.20	2.30	2.57	3.24
Hypoplastic left heart syndrome	0.93	2.05	2.35	1.86	2.92	2.68	4.24
Coarctation of aorta	1.92	2.55	2.87	2.59	2.65	2.14	2.42
Choanal atresia, bilateral	0.71	0.65	0.86	0.62	0.80	1.09	0.33
Cleft palate without cleft lip	4.35	4.77	4.80	5.76	6.90	5.06	5.11
Cleft lip with or without cleft palate	7.06	6.86	5.69	7.29	8.54	6.71	9.35
Oesophageal atresia/stenosis with or without fistula	2.00	2.47	2.59	2.96	3.33	2.55	3.36
Small intestine atresia/stenosis	1.78	1.17	2.09	1.89	2.47	2.85	2.00
Anorectal atresia/stenosis	2.42	2.57	3.21	3.23	4.11	3.56	1.09
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	0.67*
Hypospadias	5.87	6.11	9.22	9.55	12.02	12.04	10.74
Epispadias	0.29	0.12	0.26	0.21	0.23	0.19	0.15
Indeterminate sex	0.71	0.67	0.80	0.75	0.60	0.56	0.82
Renal agenesis	0.43	0.70	0.67	0.64	1.48	1.41	3.87
Cystic kidney	0.29	1.22	2.28	3.40	4.54	4.52	7.26
Bladder exstrophy	0.29	0.07	0.45	0.35	0.35	0.28	0.39
Polydactyly, preaxial	0.78	0.85	1.29	1.74	2.40	1.52	7.35
Total Limb reduction defects (include unspecified)	3.78	4.64	4.27	4.29	5.34	4.61	5.90
Transverse	2.21	2.15	2.48	2.30	2.63	2.31	2.84
Preaxial	0.43	0.77	0.71	0.52	0.78	1.09	1.33
Postaxial	0.36	0.30	0.37	0.39	0.33	0.49	0.64
Intercalary	0.29	0.65	0.32	0.52	0.43	0.34	0.51
Mixed	0.36	0.65	0.37	0.25	0.35	0.32	0.42
Unspecified	0.14	0.12	0.02	0.00	0.08	0.07	0.22
Diaphragmatic hernia	1.92	2.75	2.54	2.55	3.10	2.70	3.45
Omphalocele	0.93	1.20	1.16	1.24	2.34	2.51	3.57
Gastroschisis	0.36	0.77	0.88	1.18	1.29	1.39	2.21
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.00	0.04	0.08	0.00	2.46
Prune belly sequence	0.29	0.15	0.28	0.48	0.57	0.15	0.21
Trisomy 13	0.29	0.57	0.88	1.18	1.58	1.97	2.81
Trisomy 18	0.86	0.97	1.96	2.47	4.11	4.37	6.44
Down syndrome, all ages (include age unknown)	11.26	11.40	11.16	12.93	19.62	21.94	26.44
<20	7.76	4.72	5.68	6.10	10.98	4.78	8.93
20-24	6.52	7.48	4.93	6.49	7.54	7.56	7.63
25-29	4.78	5.27	7.47	5.79	7.83	8.43	8.89
30-34	11.61	11.08	9.49	8.91	14.12	13.10	19.48
35-39	23.14	31.35	24.18	27.94	45.30	46.50	55.81
40-44	131.11	67.64	55.20	76.75	151.21	143.79	169.20
45+	119.05	94.34	158.37	243.90	248.06	229.11	337.30
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 6 years

France: REMERA

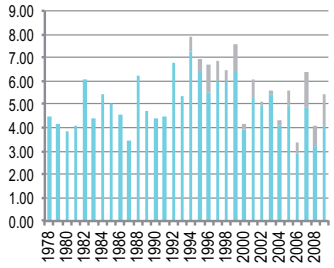
Time trends 1978-2009 (Birth prevalence rates per 10,000)



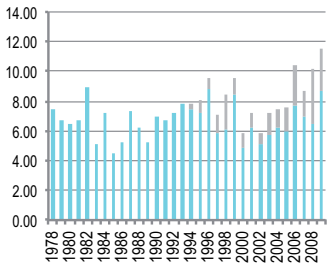
Note: L+S rates, ToP rates

France: REMERA

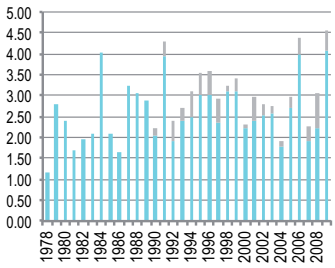
Cleft palate without cleft lip



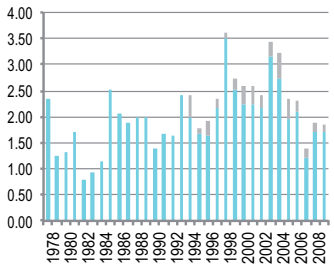
Cleft lip with or without cleft palate



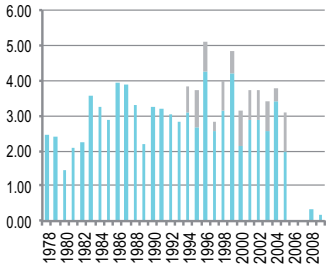
Oesophageal atresia/stenosis with or without fistula



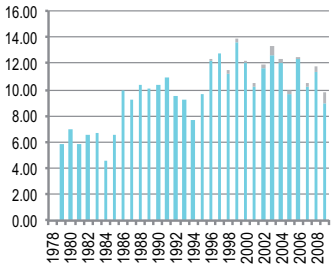
Anorectal atresia/stenosis



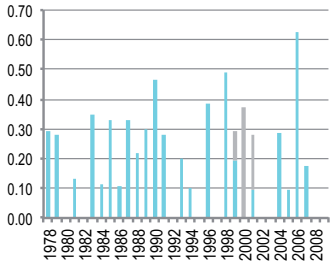
Small intestine atresia/stenosis



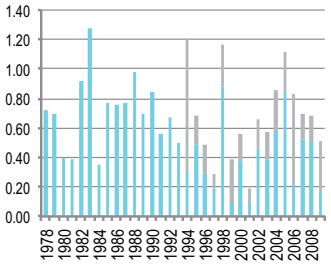
Hypospadias



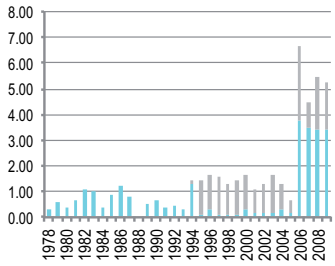
Epispadias



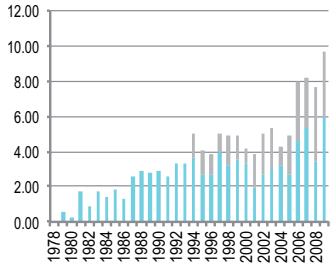
Indeterminate sex



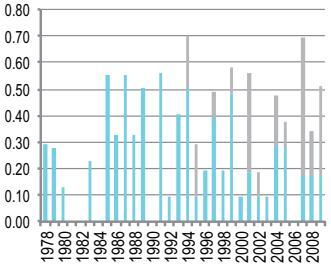
Renal agenesis



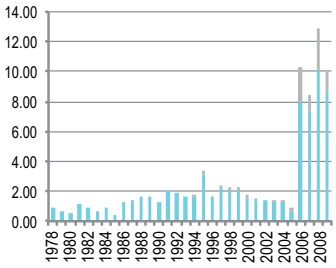
Cystic kidney



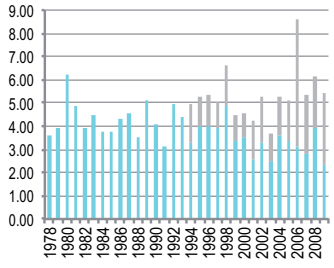
Bladder exstrophy



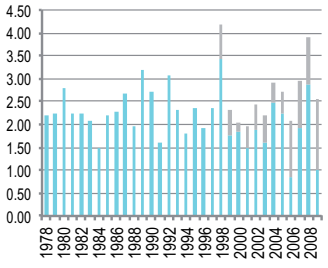
Polydactyly, preaxial



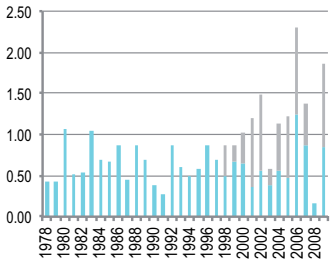
Limb reduction defects



Limb reduction defects - transverse

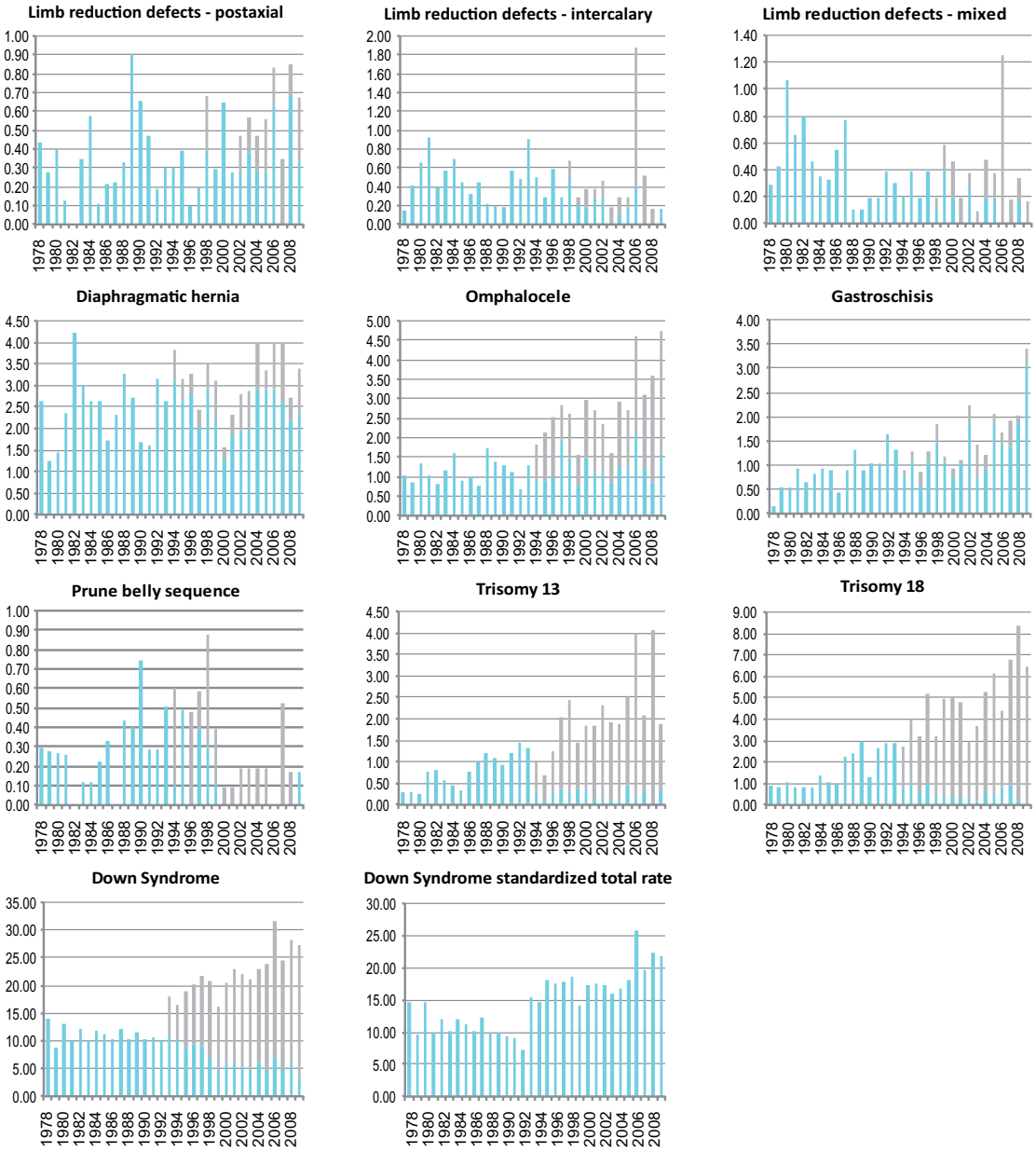


Limb reduction defects - preaxial



Note: L+S rates, ToP rates

France: REMERA



Note: L+S rates, ToP rates

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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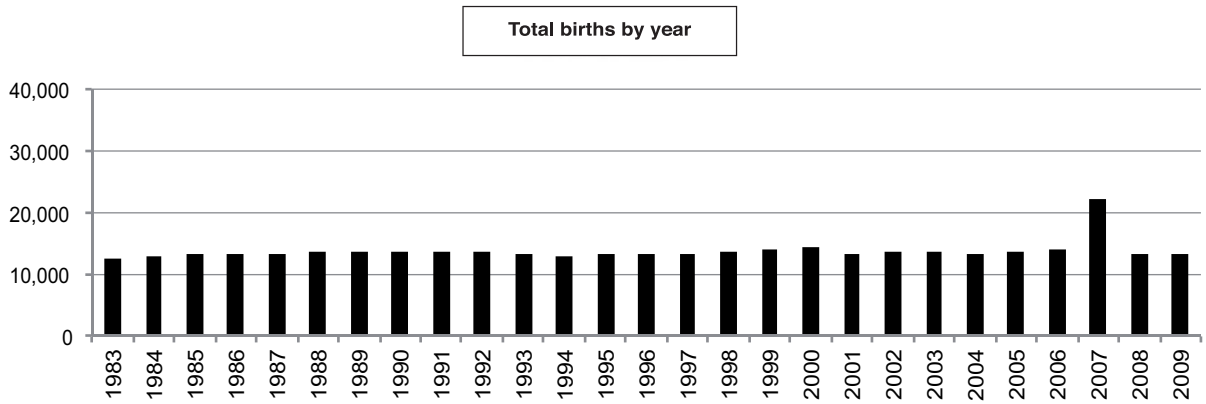
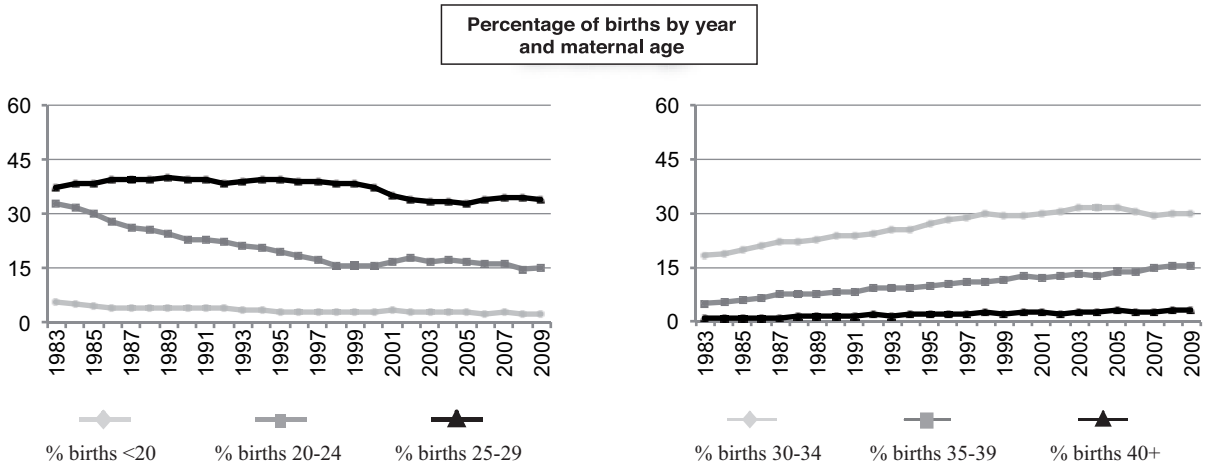
67098 Strasbourg Cedex, France
Phone: 33-3-88138120
E-mail: Berenice.Doray@chru-strasbourg.fr

France: Strasbourg





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	24	100.0	Cystic kidney	15	39.5
Spina bifida	25	73.5	Limb reduction defects	13	31.0
Encephalocele	4	80.0	Diaphragmatic hernia	4	19.0
Holoprosencephaly	10	90.9	Omphalocele	6	54.5
Hydrocephaly	27	69.2	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	8	57.1	Trisomy 13	9	69.2
Cleft palate without cleft lip	4	11.1	Trisomy 18	25	92.6
Cleft lip with or without cleft palate	11	19.6	Down syndrome	97	71.9
Renal agenesis	7	58.3			

Total ToPs with births defects = 317 (Ratio ToPs/Births: 6.54 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Strasbourg, 2009

Live births (LB)	13,009
Stillbirths (SB)	115
Total births	13,124
Number of terminations of pregnancy (ToP) for birth defects	87

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	4	3.05
Spina bifida	4	0	7	8.38
Encephalocele	0	0	2	1.52
Microcephaly	3	0	1	3.05
Holoprosencephaly	0	0	4	3.05
Hydrocephaly	4	1	7	9.14
Anophthalmos	0	0	1	0.76
Microphthalmos	2	0	0	1.52
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	2	0	0	1.52
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	4	0	0	3.05
Tetralogy of Fallot	3	0	2	3.81
Hypoplastic left heart syndrome	0	0	6	4.57
Coarctation of aorta	4	0	0	3.05
Choanal atresia, bilateral	3	0	0	2.29
Cleft palate without cleft lip	11	0	1	9.14
Cleft lip with or without cleft palate	17	0	3	15.24
Oesophageal atresia/stenosis with or without fistula	3	0	0	2.29
Small intestine atresia/stenosis	4	0	0	3.05
Anorectal atresia/stenosis	1	0	1	1.52
Undescended testis (36 weeks of gestation or later)	3	0	1	3.05
Hypospadias	26	0	1	20.57
Epispadias	1	0	0	0.76
Indeterminate sex	0	0	0	0.00
Renal agenesis	1	0	4	3.81
Cystic kidney	7	1	2	7.62
Bladder exstrophy	0	0	1	0.76
Polydactyly, preaxial	4	0	0	3.05
Total Limb reduction defects (include unspecified)	9	0	3	9.14
Transverse	2	0	1	2.29
Preaxial	4	0	2	4.57
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.76
Mixed	2	0	0	1.52
Unspecified	0	0	0	0.00
Diaphragmatic hernia	6	0	0	4.57
Omphalocele	4	0	5	6.86
Gastroschisis	3	0	0	2.29
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	3	0	3	4.57
Trisomy 18	0	0	8	6.10
Down syndrome, all ages (include age unknown)	10	0	24	25.91
<20	0	0	0	0.00
20-24	1	0	4	25.13
25-29	2	0	0	4.48
30-34	2	0	4	15.34
35-39	2	0	14	78.82
40-44	3	0	2	125.31
45+	0	0	0	0.00
unknown	0	0	0	---

nr = not reported

France: Strasbourg, Previous years rates 1983 - 2009

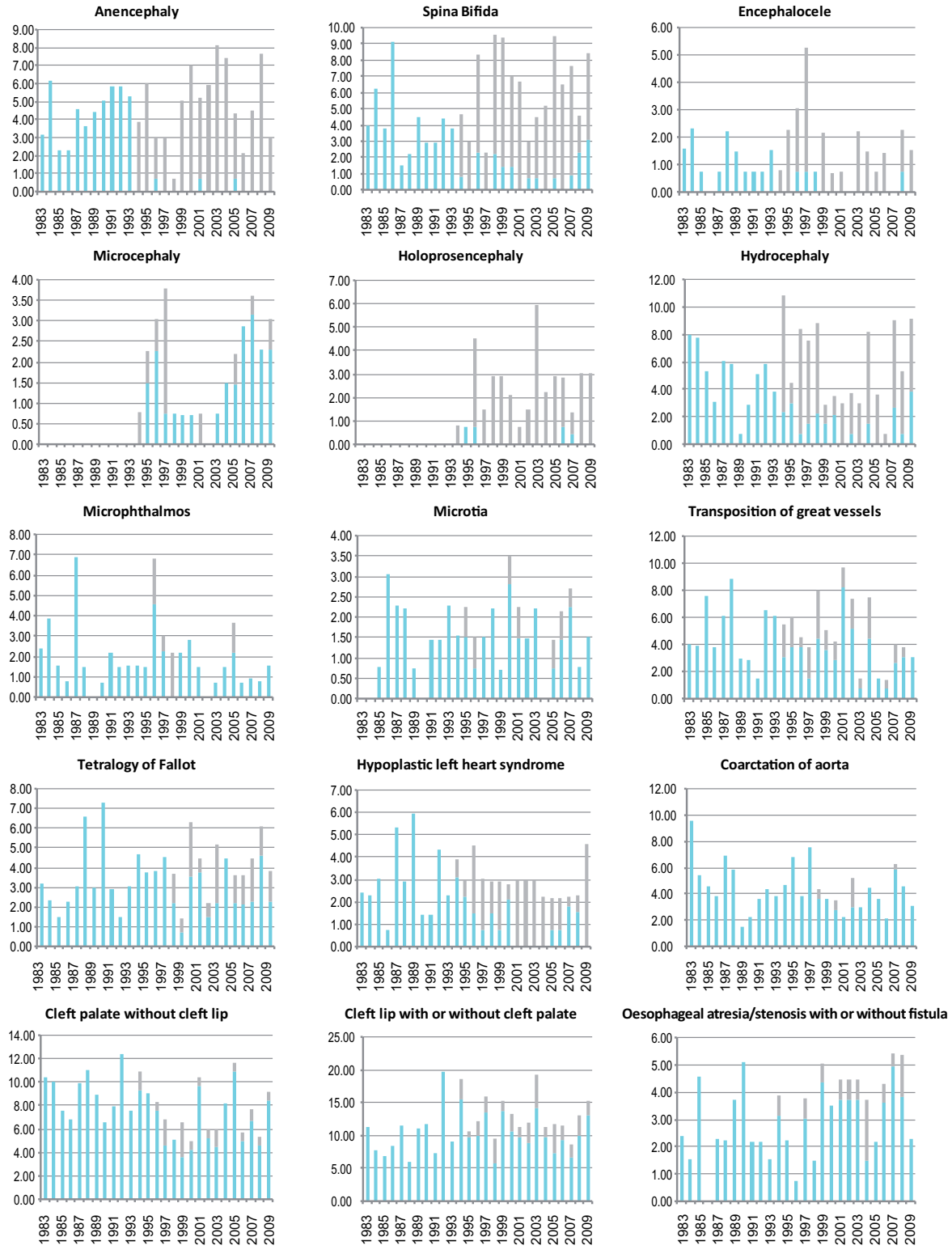
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984*	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**25,449**	**66,504**	**67,271**	**67,218**	**68,028**	**76,162**
Anencephaly		4.72	3.46	5.20	3.57	6.76	4.33
Spina bifida		5.11	4.21	3.72	6.55	5.29	7.35
Encephalocele		1.96	1.05	0.89	2.68	1.03	1.05
Microcephaly		nr	nr	0.78*	2.08	0.73	2.89
Holoprosencephaly		nr	nr	0.78*	2.53	2.50	2.49
Hydrocephaly		7.86	4.21	5.65	6.40	4.26	5.91
Anophthalmos		0.79	0.15	0.15	0.89	0.15	0.26
Microphthalmos		3.14	2.11	1.49	3.12	1.32	1.44
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.39	0.15	0.45	0.45	0.44	0.26
Microtia		0.00	1.80	1.34	1.64	1.91	1.84
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		3.93	5.86	4.46	5.50	6.03	2.89
Tetralogy of Fallot		2.75	3.31	3.86	3.42	4.56	4.33
Hypoplastic left heart syndrome		2.36	3.61	2.68	3.27	2.79	2.63
Coarctation of aorta		7.47	4.51	3.72	5.21	3.67	4.20
Choanal atresia, bilateral		nr	nr	nr	0.15	0.44	0.66
Cleft palate without cleft lip		10.22	8.87	9.07	7.14	7.06	7.88
Cleft lip with or without cleft palate		9.43	8.72	13.23	12.65	13.38	11.55
Oesophageal atresia/stenosis with or without fistula		1.96	2.56	2.97	2.68	4.12	4.07
Small intestine atresia/stenosis		nr	nr	nr	2.23	2.06	2.63
Anorectal atresia/stenosis		4.72	4.81	5.20	6.55	5.00	3.94
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	3.71*
Hypospadias		13.36	24.06	26.46	22.02	22.78	19.43
Epispadias		nr	nr	nr	0.30	0.15	0.39
Indeterminate sex		nr	nr	0.78*	0.15	1.03	0.53
Renal agenesis		nr	nr	2.33*	4.31	8.82	3.55
Cystic kidney		nr	nr	2.33*	8.93	7.20	8.01
Bladder exstrophy		nr	nr	nr	0.60	0.29	0.26
Polydactyly, preaxial		nr	nr	nr	3.72	4.26	3.41
Total Limb reduction defects (include unspecified)		6.29	6.77	6.99	12.05	8.08	8.93
Transverse		4.32	4.36	3.86	5.80	3.97	2.89
Preaxial		1.96	1.50	1.49	1.64	0.73	2.36
Postaxial		0.00	0.45	0.45	0.45	0.44	0.92
Intercalary		0.00	0.00	0.45	0.89	0.29	1.05
Mixed		0.00	0.45	0.30	0.74	1.76	1.71
Unspecified		0.00	0.00	0.00	0.00	0.59	0.00
Diaphragmatic hernia		3.14	4.06	5.35	4.46	4.56	4.20
Omphalocele		2.75	3.16	4.01	4.61	2.79	2.49
Gastroschisis		0.79	2.41	2.08	2.83	1.47	1.58
Unspecified Omphalocele/Gastroschisis		0.00	0.30	1.49	0.89	1.32	0.26
Prune belly sequence		nr	nr	nr	0.45	0.88	0.26
Trisomy 13		nr	nr	3.11*	1.79	2.65	2.63
Trisomy 18		nr	nr	3.88*	3.57	6.91	5.91
Down syndrome, all ages (include age unknown)		9.43	15.79	22.15	30.05	24.55	25.73
<20		0.00	18.21	15.49	15.58	4.76	5.00
20-24		7.31	8.37	10.79	11.22	11.33	9.88
25-29		4.16	7.64	14.02	10.39	5.51	8.89
30-34		10.57	16.78	13.90	26.11	15.45	17.91
35-39		53.07	47.42	77.08	101.90	77.49	66.92
40-44		109.89	269.46	221.37	282.80	150.94	189.30
45+		0.00	232.56	243.90	0.00	0.00	340.91
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

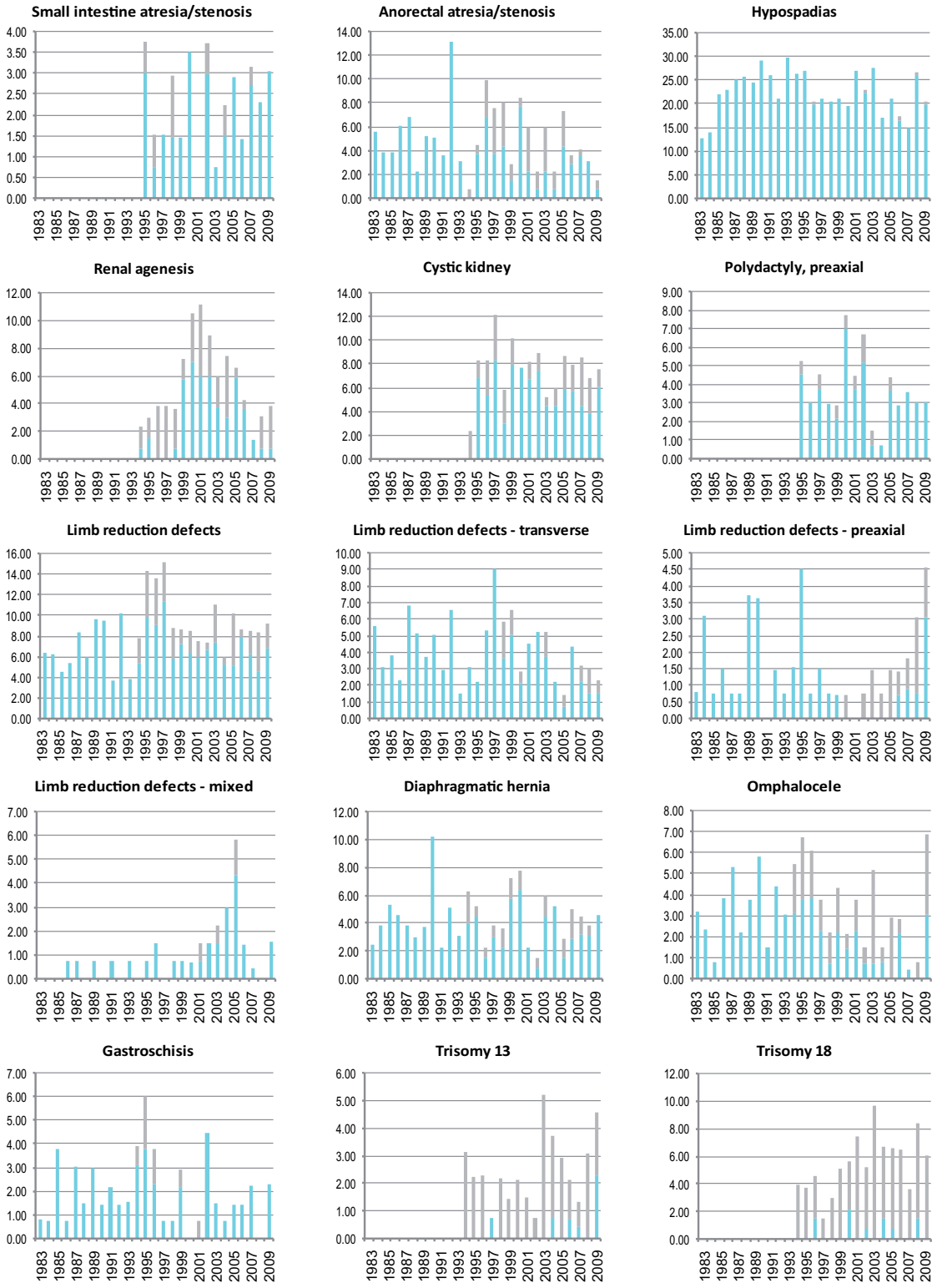
France: Strasbourg

Time trends 1983-2009 (Birth prevalence rates per 10,000)



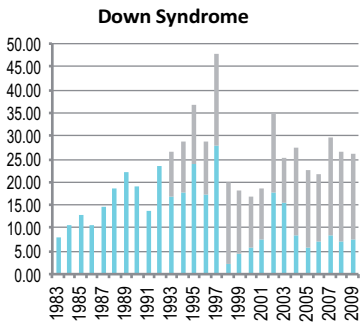
Note: L+S rates, ToP rates

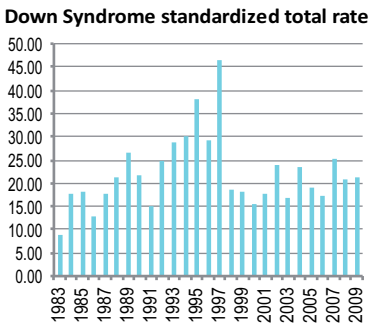
France: Strasbourg



Note: L+S rates, ToP rates

France: Strasbourg





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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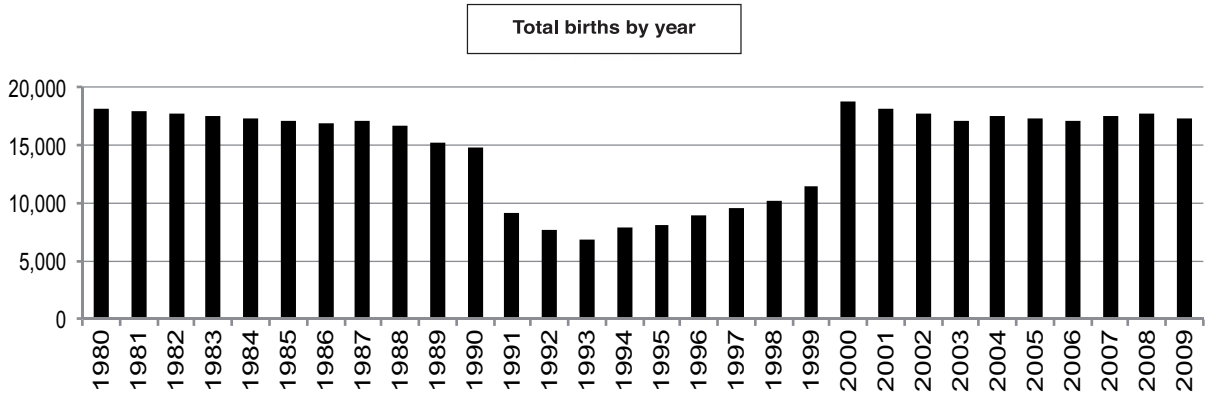
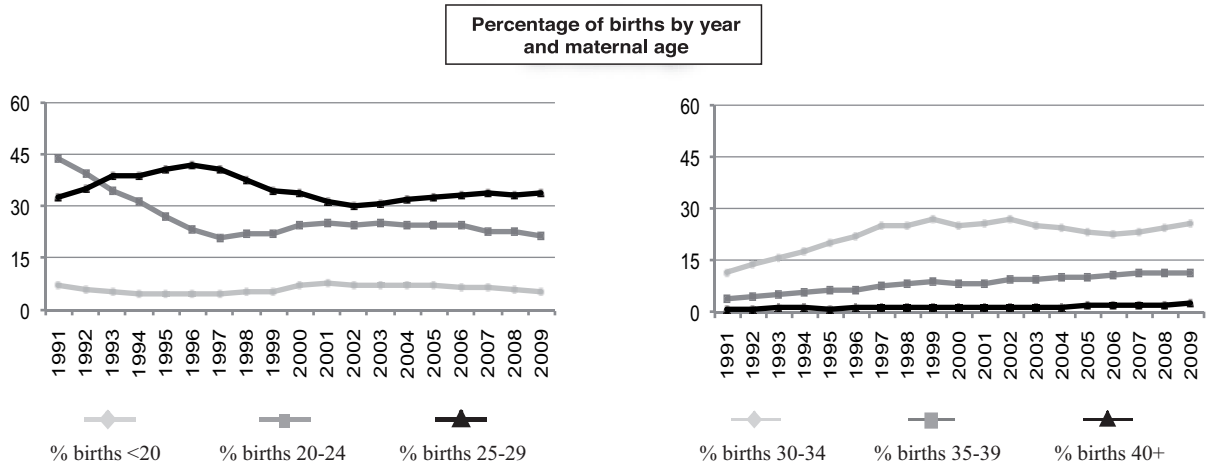
Germany: Saxony Anhalt





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	13	92.9	Cystic kidney	3	7.5
Spina bifida	25	69.4	Limb reduction defects	16	36.4
Encephalocele	4	57.1	Diaphragmatic hernia	3	16.7
Holoprosencephaly	3	75.0	Omphalocele	7	58.3
Hydrocephaly	8	40.0	Gastroschisis	1	6.7
Hypoplastic left heart syndrome	3	16.7	Trisomy 13	4	80.0
Cleft palate without cleft lip	2	5.9	Trisomy 18	19	86.4
Cleft lip with or without cleft palate	5	8.3	Down syndrome	48	56.5
Renal agenesis	5	33.3			

Total ToPs with births defects = 289 (Ratio ToPs/Births: 5.51 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Germany: Saxony Anhalt, 2009

Live births (LB)	17,144
Stillbirths (SB)	69
Total births	17,213
Number of terminations of pregnancy (ToP) for birth defects	92

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	2	1.16
Spina bifida	3	0	10	7.55
Encephalocele	1	0	0	0.58
Microcephaly	18	10	1	16.85
Holoprosencephaly	0	0	3	1.74
Hydrocephaly	3	0	3	3.49
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	2	0	0	1.16
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	1	4.65
Tetralogy of Fallot	6	0	0	3.49
Hypoplastic left heart syndrome	5	0	0	2.90
Coarctation of aorta	7	0	0	4.07
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	8	0	1	5.23
Cleft lip with or without cleft palate	15	0	0	8.71
Oesophageal atresia/stenosis with or without fistula	4	0	0	2.32
Small intestine atresia/stenosis	2	0	0	1.16
Anorectal atresia/stenosis	11	1	1	7.55
Undescended testis (36 weeks of gestation or later)	8	0	0	4.65
Hypospadias	8	0	0	4.65
Epispadias	1	0	0	0.58
Indeterminate sex	0	0	0	0.00
Renal agenesis	8	0	1	5.23
Cystic kidney	13	1	1	8.71
Bladder exstrophy	1	0	0	0.58
Polydactyly, preaxial	9	0	0	5.23
Total Limb reduction defects (include unspecified)	4	1	5	5.81
Transverse	0	0	0	0.00
Preaxial	2	0	1	1.74
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	1	0	1	1.16
Unspecified	1	1	3	2.90
Diaphragmatic hernia	3	1	2	3.49
Omphalocele	0	1	2	1.74
Gastroschisis	3	0	1	2.32
Unspecified Omphalocele/Gastroschisis	0	1	1	1.16
Prune belly sequence	0	1	1	1.16
Trisomy 13	0	0	2	1.16
Trisomy 18	0	1	7	4.65
Down syndrome, all ages (include age unknown)	12	0	14	15.10
<20	0	0	0	0.00
20-24	1	0	1	5.47
25-29	3	0	0	5.18
30-34	1	0	4	11.39
35-39	6	0	6	61.13
40-44	1	0	3	97.80
45+	0	0	0	0.00
unknown	12	0	14	---

Germany: Saxony Anhalt, Previous years rates 1980 - 2009

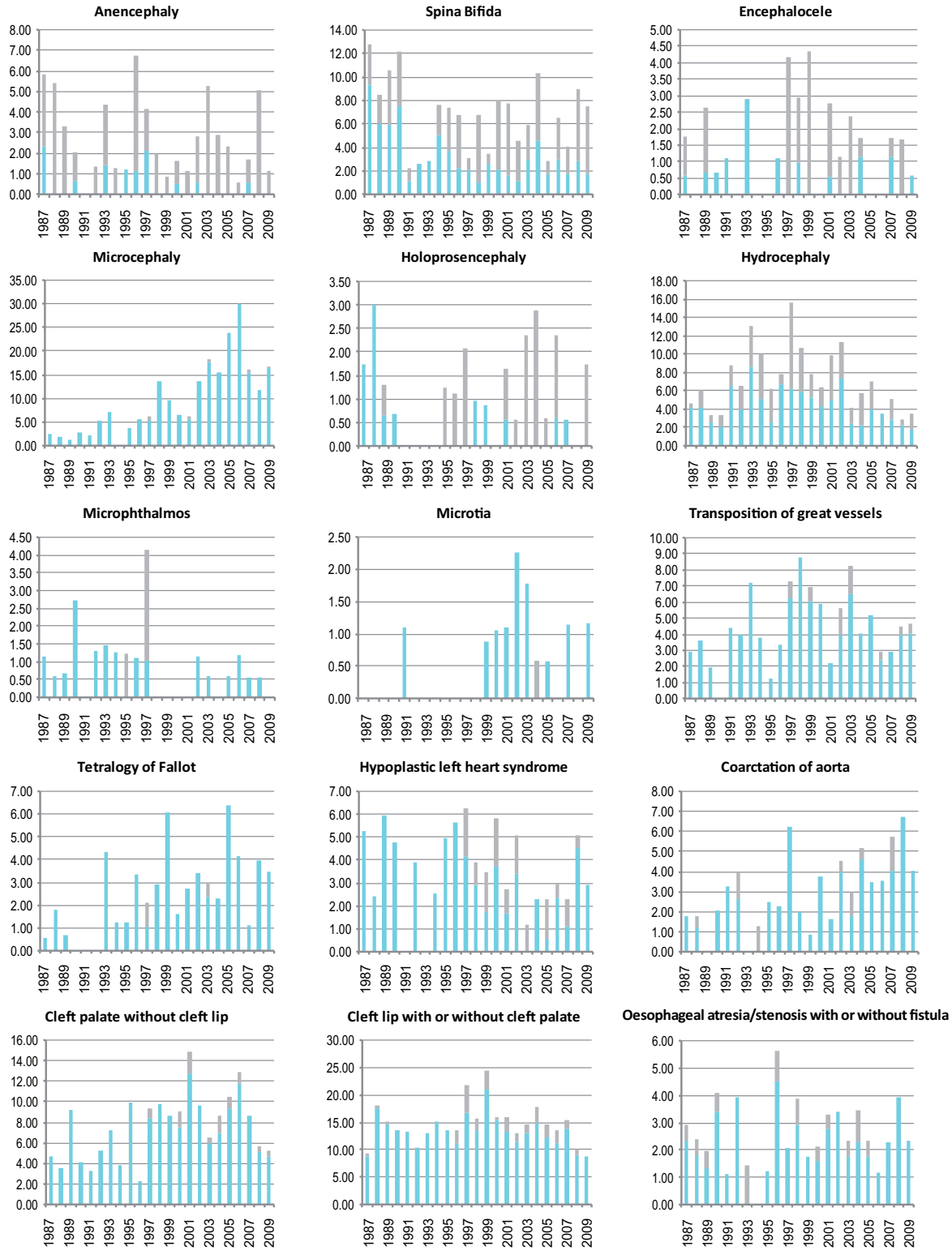
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984*	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**88,477**	**83,005**	**46,342**	**48,335**	**89,025**	**86,662**	
Anencephaly	1.70	3.86	1.73	2.90	2.70	2.19	
Spina bifida	4.18	10.24	6.47	5.38	7.30	6.00	
Encephalocele	0.57	1.20	0.86	2.69	1.57	0.81	
Microcephaly	nr	1.84*	3.24	8.07	11.79	19.62	
Holoprosencephaly	nr	2.04*	0.22	1.24	1.46	1.04	
Hydrocephaly	nr	4.69*	7.55	9.72	7.53	4.38	
Anophthalmos	nr	0.00*	0.86	0.00	0.11	0.23	
Microphthalmos	nr	0.82*	1.51	1.24	0.34	0.58	
Unspecified Anophthalmos/Microphthalmos	nr	0.00*	0.00	0.00	0.00	0.00	
Anotia	nr	0.00*	0.22	0.00	0.22	0.35	
Microtia	nr	0.00*	0.22	0.21	1.35	0.58	
Unspecified Anotia/Microtia	nr	0.00*	0.00	0.00	0.00	0.00	
Transposition of great vessels	nr	2.86*	3.24	5.79	5.17	4.04	
Tetralogy of Fallot	nr	1.02*	0.86	3.31	2.58	3.81	
Hypoplastic left heart syndrome	nr	4.49*	2.59	4.76	3.48	3.12	
Coarctation of aorta	nr	1.22*	2.16	2.69	3.59	4.73	
Choanal atresia, bilateral	nr	1.02*	1.29	0.83	0.67	0.12	
Cleft palate without cleft lip	nr	5.71*	4.53	8.07	9.77	8.54	
Cleft lip with or without cleft palate	nr	14.08*	13.16	18.21	15.50	12.46	
Oesophageal atresia/stenosis with or without fistula	nr	2.45*	2.37	2.90	2.92	2.42	
Small intestine atresia/stenosis	nr	0.82*	3.24	1.24	2.58	1.50	
Anorectal atresia/stenosis	nr	3.47*	3.45	2.69	2.92	6.35	
Undescended testis (36 weeks of gestation or later)	nr	11.84*	18.77	12.21	9.44	7.62	
Hypospadias	nr	14.49*	17.05	17.79	8.87	7.15	
Epispadias	nr	0.20*	0.43	0.62	0.34	0.46	
Indeterminate sex	nr	0.61*	0.00	0.83	0.90	0.23	
Renal agenesis	nr	1.84*	1.08	3.10	2.25	2.08	
Cystic kidney	nr	2.04*	3.67	4.14	5.17	8.54	
Bladder exstrophy	nr	0.82*	0.22	0.62	0.00	0.35	
Polydactyly, preaxial	nr	0.00*	1.94	4.34	3.59	4.73	
Total Limb reduction defects (include unspecified)	nr	4.29*	7.34	8.28	7.86	6.92	
Transverse	nr	nr	nr	nr	3.37	1.50	
Preaxial	nr	nr	nr	nr	0.56	0.58	
Postaxial	nr	nr	nr	nr	0.00	0.58	
Intercalary	nr	nr	nr	nr	1.68	0.35	
Mixed	nr	nr	nr	nr	1.80	2.88	
Unspecified	nr	nr	nr	nr	0.45	1.04	
Diaphragmatic hernia	nr	1.43*	1.51	1.24	2.70	3.00	
Omphalocele	nr	5.72*	2.37	2.90	3.15	3.12	
Gastroschisis	nr	1.02*	2.37	3.72	3.71	3.81	
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	0.11	0.23	
Prune belly sequence	nr	0.00*	0.86	1.24	0.79	0.46	
Trisomy 13	0.23	0.36	0.65	2.48	0.79	1.15	
Trisomy 18	0.90	0.84	0.86	1.66	3.37	3.81	
Down syndrome, all ages (include age unknown)	8.59	8.19	10.36	16.96	16.40	15.92	
<20	nr	nr	nr	nr	6.15	0.00	
20-24	nr	nr	nr	nr	6.36	9.95	
25-29	nr	nr	nr	nr	9.60	6.59	
30-34	nr	nr	nr	nr	12.83	14.57	
35-39	nr	nr	nr	nr	53.03	47.75	
40-44	nr	nr	nr	nr	174.19	119.05	
45+	nr	nr	nr	nr	392.16	273.97	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

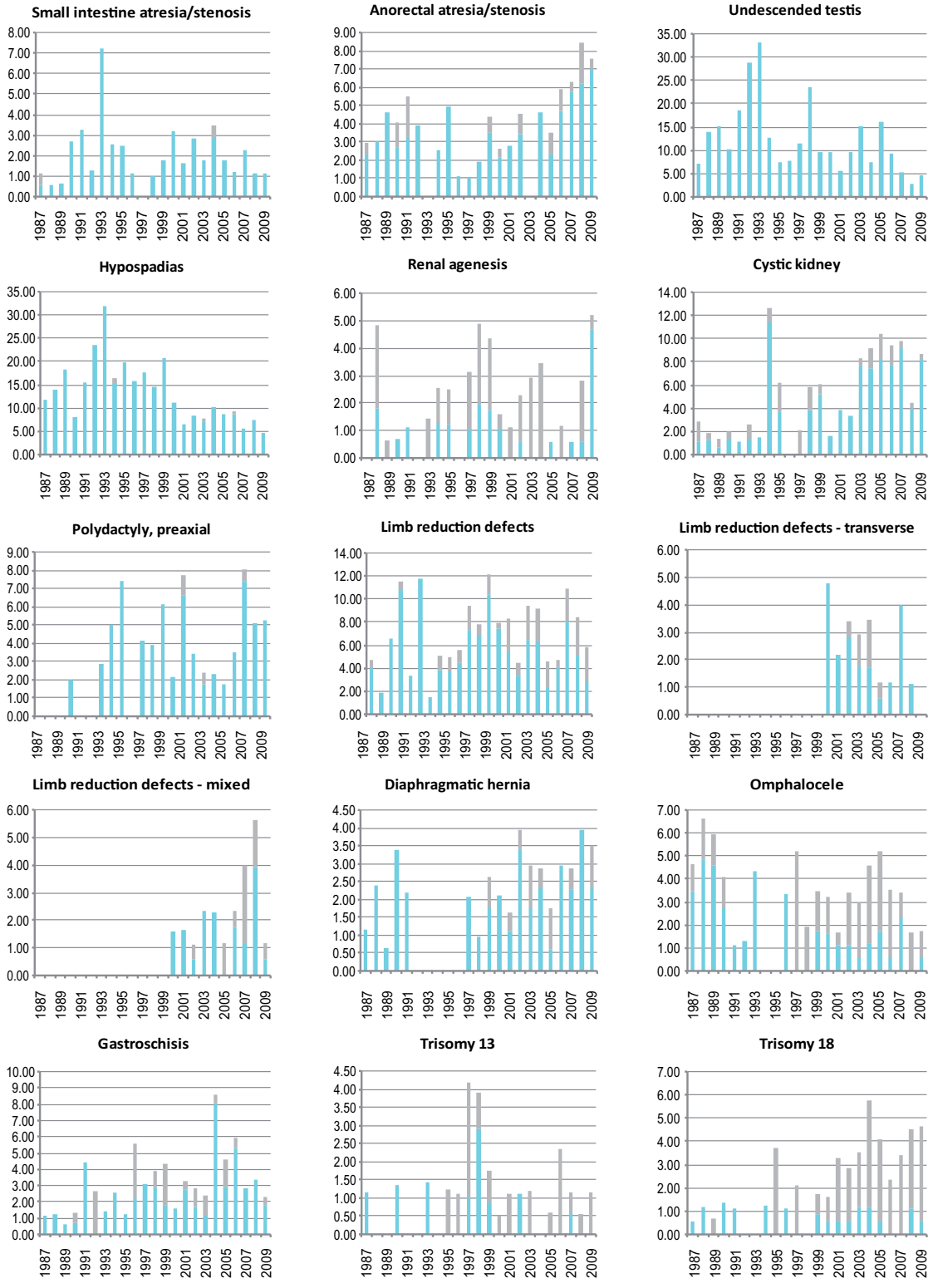
Germany: Saxony Anhalt

Time trends 1987-2009 (Birth prevalence rates per 10,000)



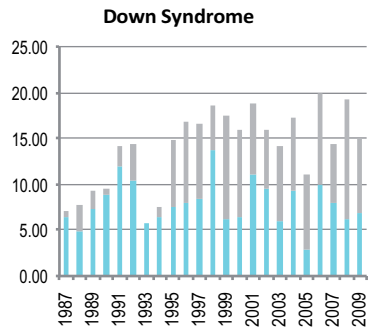
Note: L+S rates, ToP rates

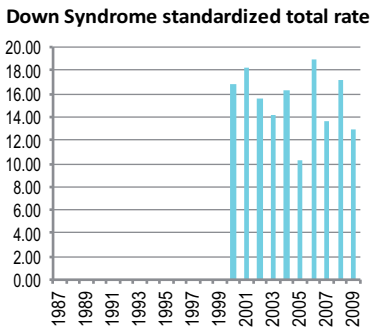
Germany: Saxony Anhalt



Note: L+S rates, ToP rates

Germany: Saxony Anhalt





Note: L+S rates, ToP rates

Hungary
Hungarian Congenital Abnormality Registry

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

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

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

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

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

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

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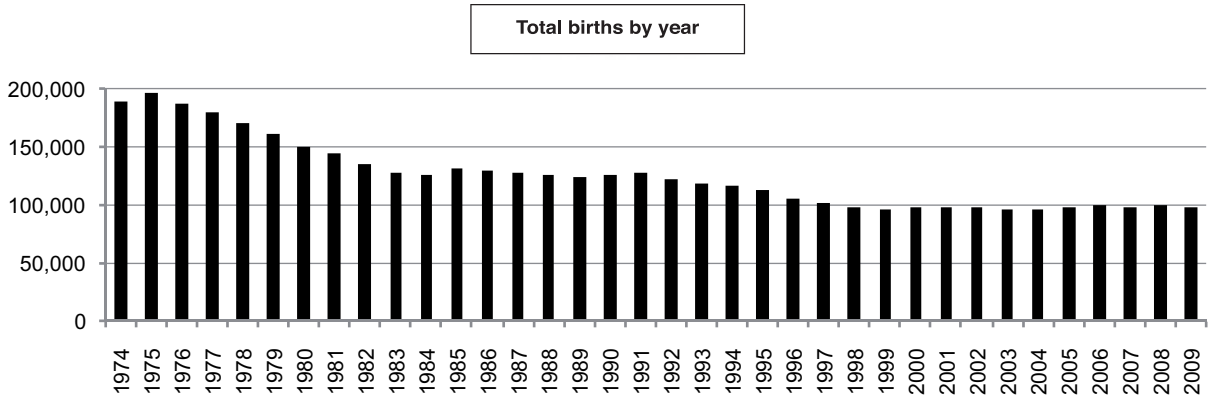
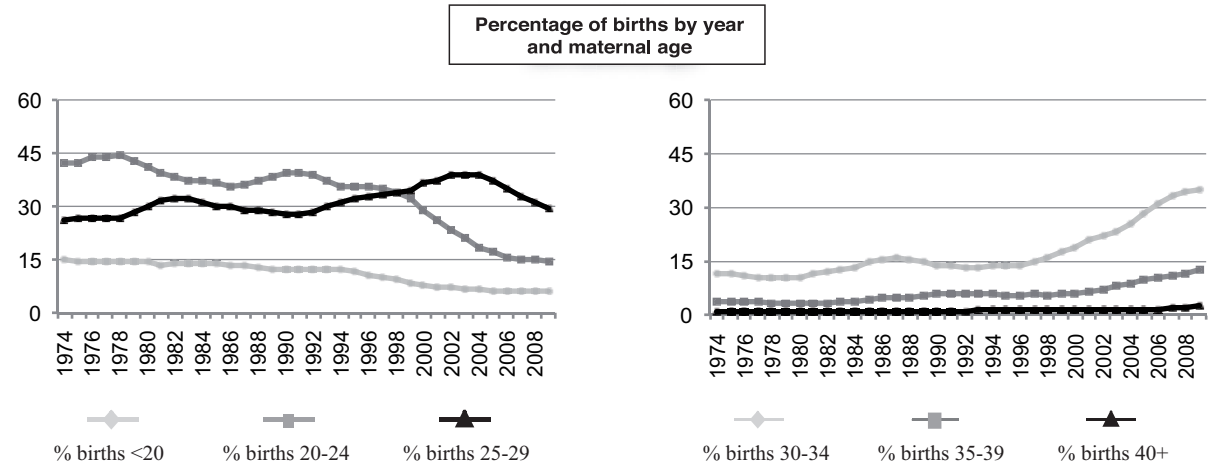




Terminations of Pregnancy (ToPs) in selected malformations (2007-2009)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	55	91.7	Cystic kidney	47	30.9
Spina bifida	89	65.9	Limb reduction defects	20	18.3
Encephalocele	16	66.7	Diaphragmatic hernia	11	14.7
Holoprosencephaly	18	60.0	Omphalocele	26	50.0
Hydrocephaly	78	42.2	Gastroschisis	27	79.4
Hypoplastic left heart syndrome	20	24.1	Trisomy 13	31	77.5
Cleft palate without cleft lip	0	0.0	Trisomy 18	71	76.3
Cleft lip with or without cleft palate	21	9.0	Down syndrome	282	51.7
Renal agenesis	20	40.0			

Total ToPs with births defects = 1,264 (Ratio ToPs/Births: 4.29 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Hungary, 2009

Live births (LB)	96,442
Stillbirths (SB)	519
Total births	96,961
Number of terminations of pregnancy (ToP) for birth defects	457

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	19	2.06
Spina bifida	14	1	28	4.43
Encephalocele	3	0	8	1.13
Microcephaly	17	0	1	1.86
Holoprosencephaly	7	1	10	1.86
Hydrocephaly	41	1	27	7.12
Anophthalmos	3	0	0	0.31
Microphthalmos	12	0	1	1.34
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	7	0	0	0.72
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	28	0	3	3.20
Tetralogy of Fallot	32	0	0	3.30
Hypoplastic left heart syndrome	15	0	5	2.06
Coarctation of aorta	40	0	0	4.13
Choanal atresia, bilateral (*)	7	0	0	0.72
Cleft palate without cleft lip	47	1	0	4.95
Cleft lip with or without cleft palate	79	0	12	9.39
Oesophageal atresia/stenosis with or without fistula	33	0	0	3.40
Small intestine atresia/stenosis	23	0	0	2.37
Anorectal atresia/stenosis	29	0	1	3.09
Undescended testis (36 weeks of gestation or later)	215	0	0	22.17
Hypospadias	287	0	0	29.60
Epispadias	2	0	0	0.21
Indeterminate sex	4	0	0	0.41
Renal agenesis	2	0	2	0.41
Cystic kidney	33	1	18	5.36
Bladder exstrophy	2	0	0	0.21
Polydactyly, preaxial (§)	94	0	4	10.11
Total Limb reduction defects (include unspecified)	35	0	8	4.43
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	24	0	5	2.99
Omphalocele	10	0	12	2.27
Gastroschisis	5	0	7	1.24
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	5	0	10	1.55
Trisomy 18	9	0	30	4.02
Down syndrome, all ages (include age unknown)	83	3	117	20.94
<20	5	1	0	10.12
20-24	8	0	2	7.04
25-29	12	0	10	7.71
30-34	22	0	28	14.82
35-39	19	1	45	52.58
40-44	12	1	30	201.69
45+	0	0	0	0.00
unknown	5	0	2	---

nr = not reported
(*) Choanal atresia, unilateral and bilateral are included.
(§) Polydactyly no specified without syndactyly. Number of syndactyly is 11 (live births).

Hungary, Previous years rates 1974 - 2009

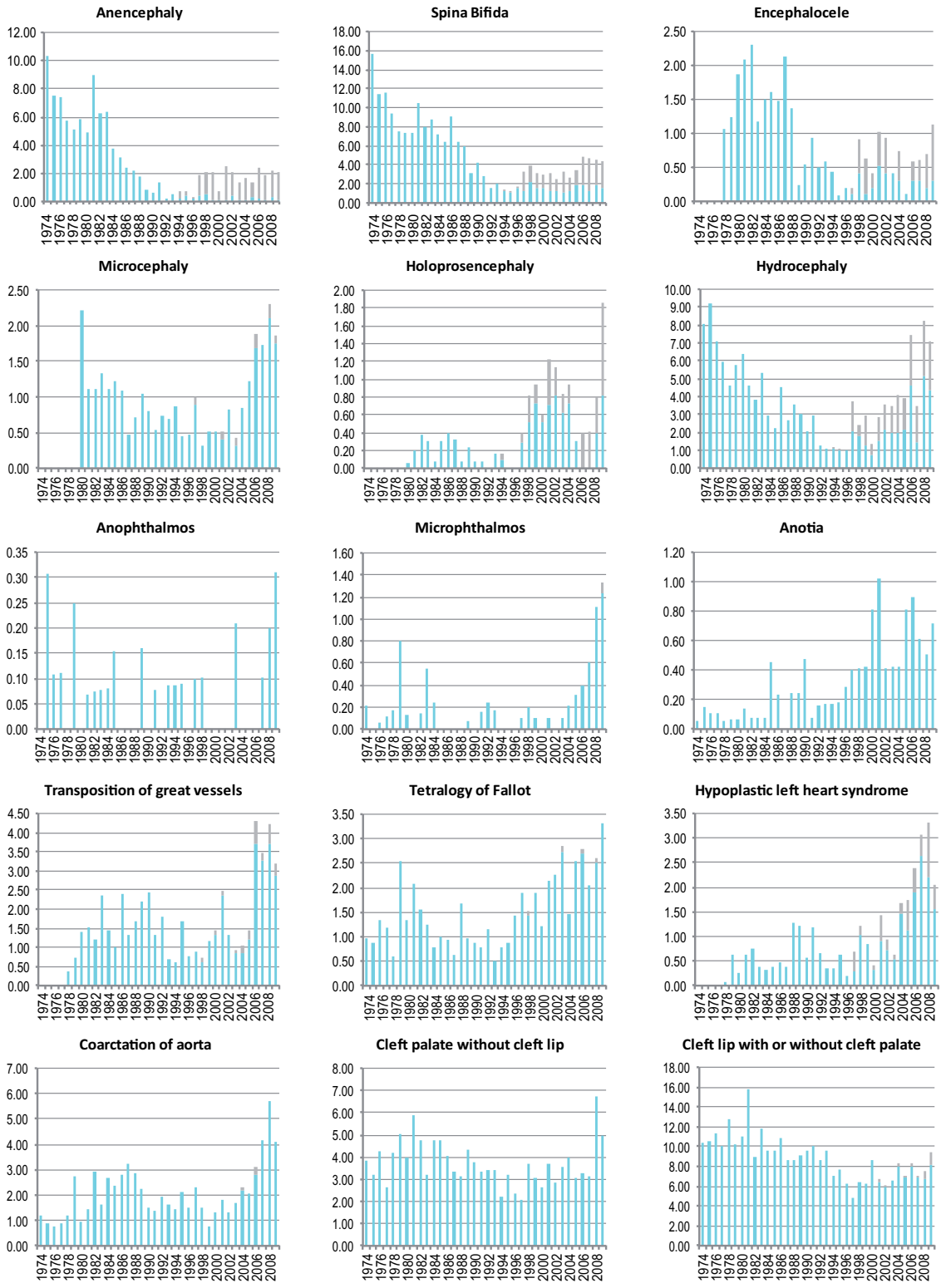
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**1,081,073**	**682,788**	**635,779**	**609,857**	**511,919**	**483,849**	**493,001**
Anencephaly	7.08	6.12	2.08	0.69	1.37	1.65	1.97
Spina bifida	10.63	8.38	6.23	2.44	2.60	2.93	4.40
Encephalocele	1.15*	1.80	1.37	0.61	0.39	0.70	0.63
Microcephaly	nr	1.39	0.91	0.72	0.55	0.62	1.81
Holoprosencephaly	nr	0.21	0.27	0.10	0.41	0.95	0.75
Hydrocephaly	6.86	4.66	3.21	1.74	2.21	3.06	6.04
Anophthalmos	0.13	0.06	0.06	0.05	0.06	0.04	0.12
Microphthalmos	0.21	0.21	0.02	0.11	0.08	0.08	0.75
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	nr	nr	nr
Anotia	0.09	0.09	0.24	0.21	0.33	0.62	0.71
Microtia	0.05	0.03	0.02	0.02	0.02	0.10	0.14
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.54*	1.57	1.71	1.39	1.05	1.45	3.33
Tetralogy of Fallot	1.22	1.42	1.04	0.82	1.50	1.98	2.66
Hypoplastic left heart syndrome	0.33*	0.47	0.74	0.62	0.70	1.01	2.52
Coarctation of aorta	1.23	1.89	2.71	1.59	1.66	1.69	3.83
Choanal atresia, bilateral	nr	0.15	0.14	0.16	0.02	0.06	0.67
Cleft palate without cleft lip	3.83	4.54	3.92	3.26	2.87	3.35	4.24
Cleft lip with or without cleft palate	10.84	11.50	9.39	9.02	6.27	7.27	7.85
Oesophageal atresia/stenosis with or without fistula	2.06*	1.74	1.71	1.41	0.92	0.93	2.23
Small intestine atresia/stenosis	nr	1.51	1.18	1.07	0.51	0.95	2.09
Anorectal atresia/stenosis	2.20*	2.28	1.84	1.57	0.90	0.95	2.39
Undescended testis (36 weeks of gestation or later)	nr	17.81	16.28	15.05	10.67	12.83	20.93
Hypospadias	15.60	20.93	21.17	21.37	19.42	22.07	27.85
Epispadias	nr	nr	nr	nr	nr	nr	0.30*
Indeterminate sex	nr	0.29	0.36	0.18	0.16	0.41	0.39
Renal agenesis	1.27*	1.04	1.04	0.89	0.20	0.35	1.28
Cystic kidney	nr	0.00	0.19	0.49	1.35	2.46	4.75
Bladder exstrophy	nr	0.34	0.44	0.07	0.06	0.10	0.28
Polydactyly, preaxial	nr	0.94	1.90	1.31	4.98	8.18	7.14
Total Limb reduction defects (include unspecified)	nr	4.01*	4.29	2.77	3.05	3.27	3.65
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	1.81	2.62	2.00	1.75	0.92	0.43	2.35
Omphalocele	nr	2.13*	1.27	0.85	0.74	1.12	1.52
Gastroschisis	nr	0.49*	0.50	0.61	0.61	0.70	1.20
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	nr	nr
Prune belly sequence	nr	nr		0.00*	0.10	0.00	0.06
Trisomy 13	nr	0.15*	0.25	0.20	0.20	0.72	1.12
Trisomy 18	nr	0.23*	0.30	0.25	0.47	1.65	2.74
Down syndrome, all ages (include age unknown)	8.93	8.17	8.26	8.53	6.82	14.14	17.40
<20	nr	1.85*	1.91	1.45	1.92	6.24	9.47
20-24	nr	1.50*	3.03	2.31	2.89	6.71	7.71
25-29	nr	3.15*	4.50	3.06	2.76	8.82	7.58
30-34	nr	4.53*	5.41	4.50	5.33	13.87	14.10
35-39	nr	9.71*	14.43	22.94	13.58	39.32	46.93
40+	nr	74.36*	48.29	86.88	79.82	167.65	148.98
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years or 6 years

Hungary

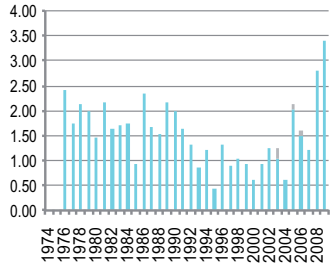
Time trends 1974-2009 (Birth prevalence rates per 10,000)



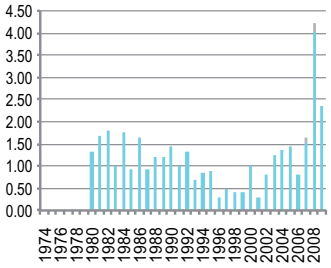
Note: L+S rates, ToP rates

Hungary

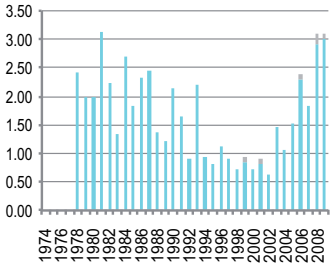
Oesophageal atresia/stenosis with or without fistula



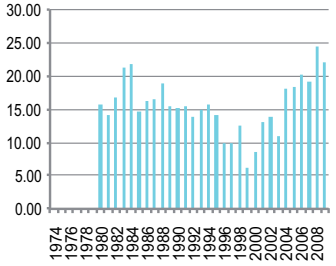
Small intestine atresia/stenosis



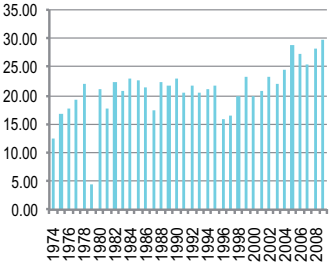
Anorectal atresia/stenosis



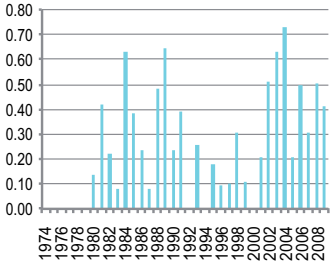
Undescended testis



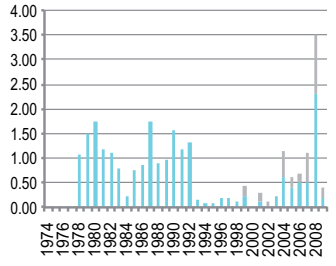
Hypospadias



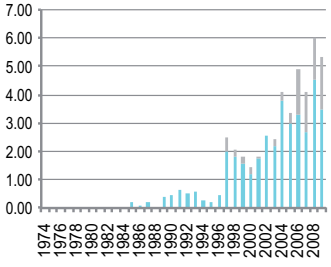
Indeterminate sex



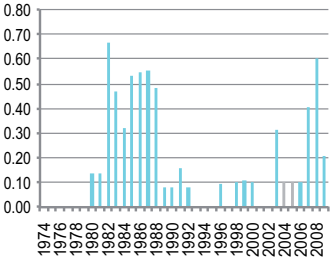
Renal agenesis



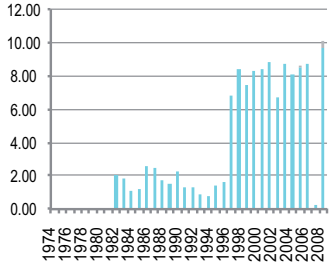
Cystic kidney



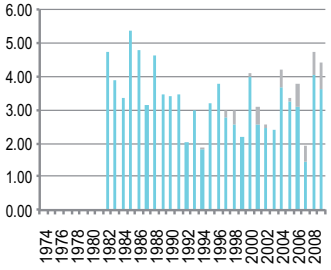
Bladder exstrophy



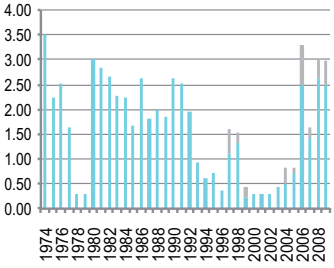
Polydactyly, preaxial



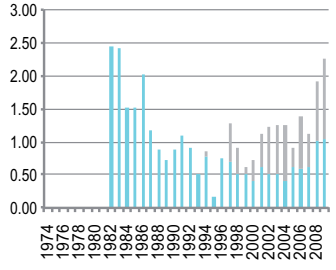
Limb reduction defects



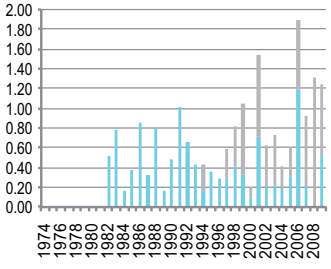
Diaphragmatic hernia



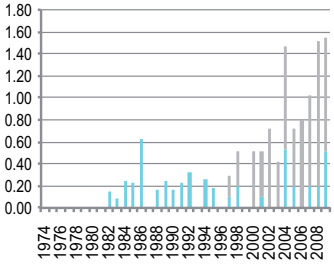
Omphalocele



Gastroschisis

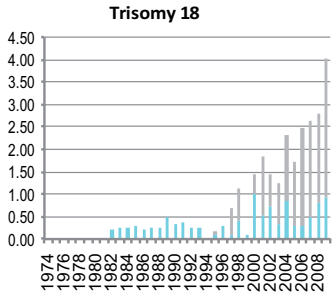


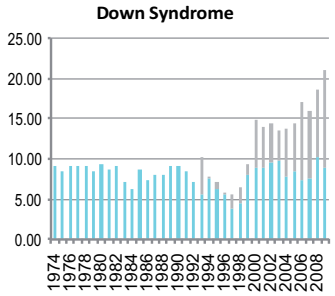
Trisomy 13

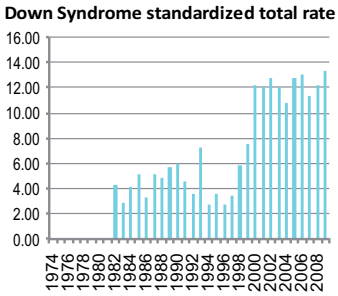


Note: L+S rates, ToP rates

Hungary







Note: L+S rates, ToP rates

India: BDRI
Birth Defects Registry of India

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

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

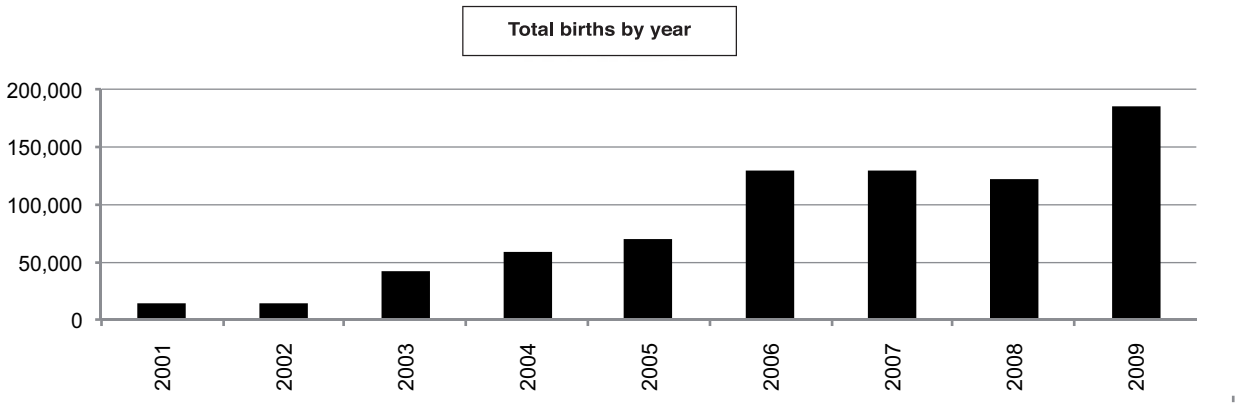
Sources of ascertainment:
All our contributing hospitals are Obstetrics hospitals and the idea of Paediatricians and neonatologists contributing is just picking up.

Exposure information:
We do not have any exposure information.

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

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

India: BDRI



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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	275	51.3	Cystic kidney	49	35.0
Spina bifida	190	35.9	Limb reduction defects	14	13.7
Encephalocele	64	51.2	Diaphragmatic hernia	29	25.7
Holoprosencephaly	19	52.8	Omphalocele	46	41.8
Hydrocephaly	104	25.7	Gastroschisis	19	51.4
Hypoplastic left heart syndrome	22	45.8	Trisomy 13	2	100.0
Cleft palate without cleft lip	7	10.4	Trisomy 18	7	53.8
Cleft lip with or without cleft palate	39	16.3	Down syndrome	16	32.7
Renal agenesis	35	49.3			

Total ToPs with births defects = 1,076 (Ratio ToPs/Births: 2.46 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

India: BDRI, 2009

Live births (LB)	180,379
Stillbirths (SB)	5,019
Total births	185,398
Number of terminations of pregnancy (ToP) for birth defects	451

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	16	94	104	11.54
Spina bifida	91	64	82	12.78
Encephalocele	5	20	26	2.75
Microcephaly	22	7	5	1.83
Holoprosencephaly	2	8	6	0.86
Hydrocephaly	52	75	46	9.33
Anophthalmos	2	0	2	0.22
Microphthalmos	6	1	0	0.38
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.11
Microtia	3	0	0	0.16
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	2	5	0.70
Tetralogy of Fallot	6	0	2	0.43
Hypoplastic left heart syndrome	4	5	8	0.92
Coarctation of aorta	1	0	0	0.05
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	21	5	2	1.51
Cleft lip with or without cleft palate	57	9	24	4.85
Oesophageal atresia/stenosis with or without fistula	34	4	4	2.27
Small intestine atresia/stenosis	16	2	2	1.08
Anorectal atresia/stenosis	15	5	4	1.29
Undescended testis (36 weeks of gestation or later)	22	0	0	1.19
Hypospadias	40	1	1	2.27
Epispadias	1	0	0	0.05
Indeterminate sex	22	14	1	2.00
Renal agenesis	8	12	9	1.56
Cystic kidney	32	8	15	2.97
Bladder exstrophy	3	0	0	0.16
Polydactyly, preaxial	54	4	4	3.34
Total Limb reduction defects (include unspecified)	31	12	9	2.80
Transverse	0	0	0	0.00
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	0	0	0.00
Diaphragmatic hernia	30	7	12	2.64
Omphalocele	12	16	24	2.80
Gastroschisis	7	3	12	1.19
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	3	0	1	0.22
Trisomy 13	0	0	2	0.11
Trisomy 18	2	2	2	0.32
Down syndrome, all ages (include age unknown)	11	3	7	1.13
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported

India: BDRI, Previous years rates 2001 - 2009

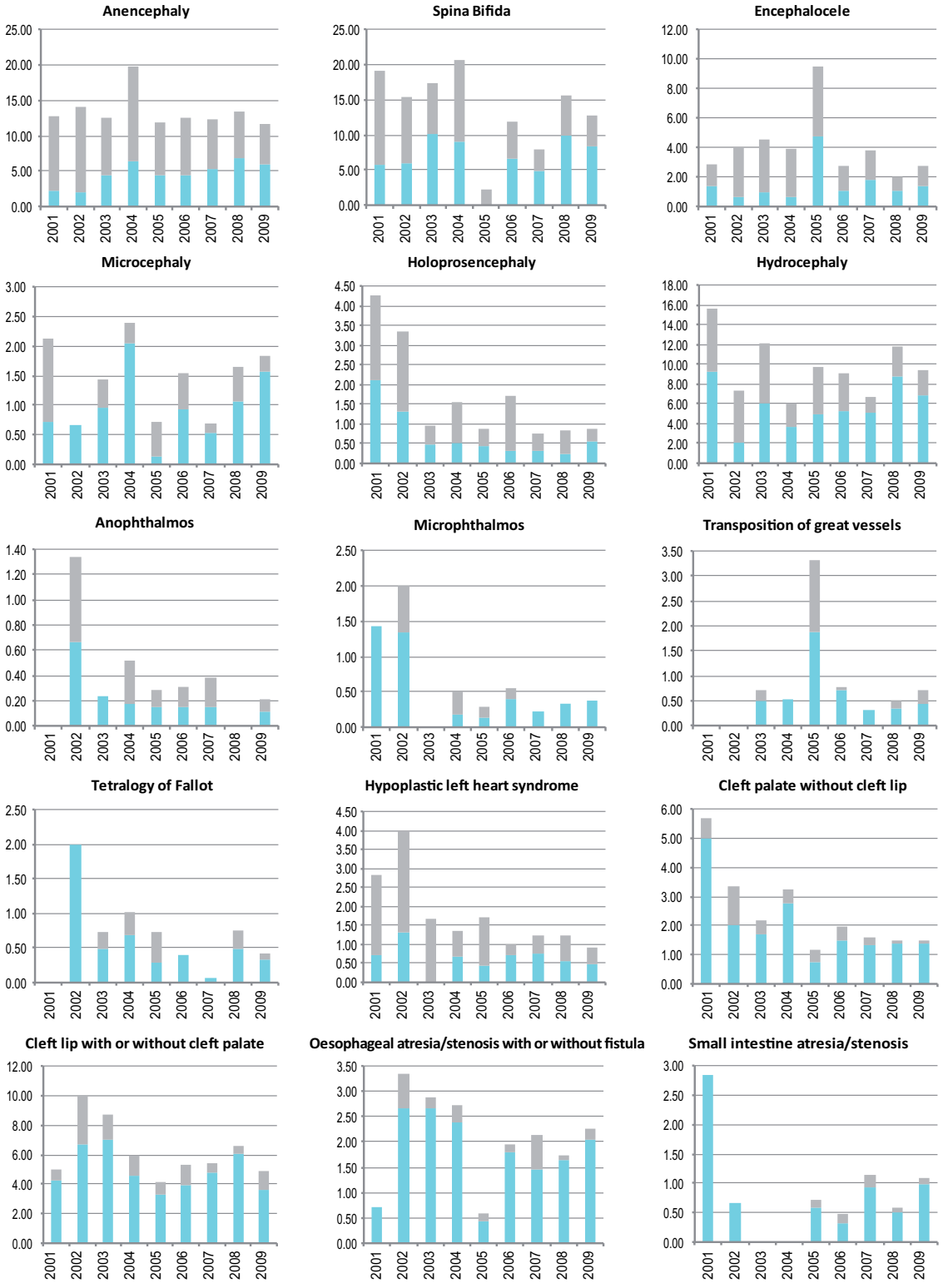
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-19992000-2004*	2005-2009
Total births					**129,083**	**634,838**
Anencephaly					16.04	12.26
Spina bifida					18.83	11.01
Encephalocele					4.03	3.56
Microcephaly					1.86	1.39
Holoprosencephaly					1.86	1.01
Hydrocephaly					9.14	9.25
Anophthalmos					0.46	0.24
Microphthalmos					0.62	0.36
Unspecified Anophthalmos/Microphthalmos					0.00	0.02
Anotia					0.00	0.06
Microtia					0.08	0.06
Unspecified Anotia/Microtia					0.00	0.00
Transposition of great vessels					0.46	0.88
Tetralogy of Fallot					0.93	0.44
Hypoplastic left heart syndrome					1.94	1.15
Coarctation of aorta					1.08	0.11
Choanal atresia, bilateral					0.08	0.08
Cleft palate without cleft lip					3.18	1.58
Cleft lip with or without cleft palate					7.20	5.32
Oesophageal atresia/stenosis with or without fistula					2.63	1.89
Small intestine atresia/stenosis					0.39	0.83
Anorectal atresia/stenosis					0.54	1.91
Undescended testis (36 weeks of gestation or later)					1.16	1.09
Hypospadias					2.17	2.00
Epispadias					0.00	0.02
Indeterminate sex					2.87	1.69
Renal agenesis					3.80	1.70
Cystic kidney					5.27	3.10
Bladder exstrophy					0.62	0.47
Polydactyly, preaxial					3.18	3.37
Total Limb reduction defects (include unspecified)					5.58	5.56
Transverse					nr	nr
Preaxial					nr	nr
Postaxial					nr	nr
Intercalary					nr	nr
Mixed					nr	nr
Unspecified					nr	nr
Diaphragmatic hernia					4.42	2.52
Omphalocele					3.56	2.47
Gastroschisis					0.46	0.83
Unspecified Omphalocele/Gastroschisis					0.00	0.11
Prune belly sequence					0.23	0.20
Trisomy 13					0.31	0.05
Trisomy 18					0.46	0.39
Down syndrome, all ages (include age unknown)					0.85	1.10
<20					nr	nr
20-24					nr	nr
25-29					nr	nr
30-34					nr	nr
35-39					nr	nr
40-44					nr	nr
45+					nr	nr
unknown					---	---

nr = not reported
* data include less than 5 years

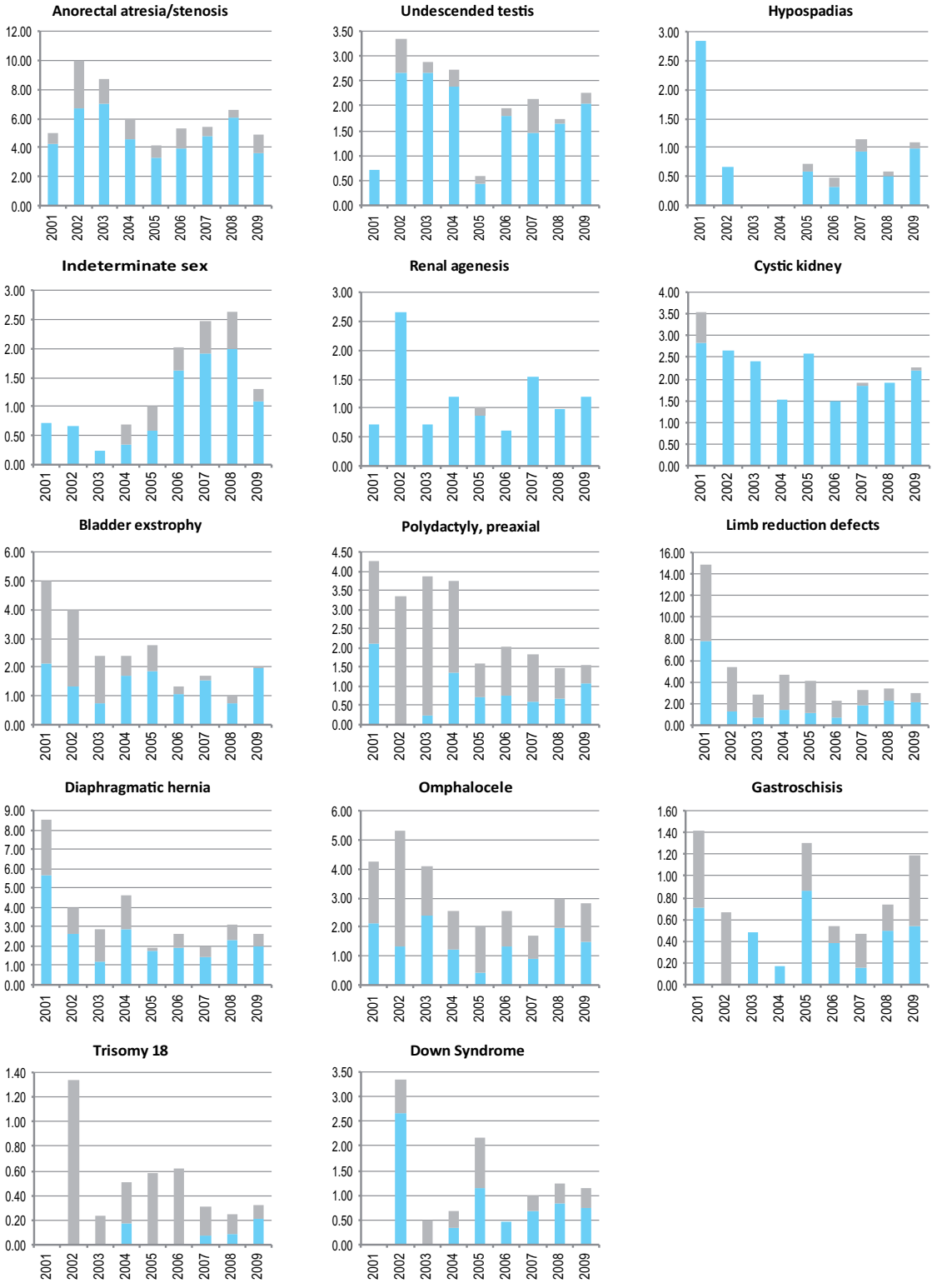
India: BDRI

Time trends 2001-2009 (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.

Size and coverage:
TROCA is a hospital-based registry and situated in the North-West 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 (15000 births per year) in the area.

Legislation and funding:
The programme has been financially supported by the National Public Health Management Centre (NPMC) as a research grant. TROCA is located in the Alzahra University hospital of Tabriz University of Medical Sciences.

Exposure information:
Some exposure information are 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.

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E-mail: saeed.dastgiri@gmail.com
Website: http://troca.tbzmed.ac.ir

Iran:TRoCA, 2009

Live births (LB)	22,993
Stillbirths (SB)	203
Total births	23,196
Number of terminations of pregnancy (ToP) for birth defects	27

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	4	4	4.74
Spina bifida	1	nr	1	0.86
Encephalocele	nr	1	1	0.86
Microcephaly	4	nr	2	2.59
Holoprosencephaly	2	nr	nr	0.86
Hydrocephaly	22	1	4	11.64
Anophthalmos	nr	nr	nr	nr
Microphthalmos	5	nr	nr	2.16
Unspecified Anophthalmos/Microphthalmos	2	nr	nr	0.86
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	2	nr	nr	0.86
Transposition of great vessels	22	nr	nr	9.48
Tetralogy of Fallot	2	nr	nr	0.86
Hypoplastic left heart syndrome	nr	nr	nr	nr
Coarctation of aorta	12	nr	nr	5.17
Choanal atresia, bilateral	nr	nr	nr	nr
Cleft palate without cleft lip	12	1	1	6.04
Cleft lip with or without cleft palate	15	1	nr	6.90
Oesophageal atresia/stenosis with or without fistula	24	nr	nr	10.35
Small intestine atresia/stenosis	22	nr	nr	9.48
Anorectal atresia/stenosis	41	nr	nr	17.68
Undescended testis (36 weeks of gestation or later)	18	1	nr	8.19
Hypospadias	34	nr	nr	14.66
Epispadias	nr	nr	nr	nr
Indeterminate sex	7	nr	nr	3.02
Renal agenesis	nr	nr	nr	nr
Cystic kidney	10	3	nr	5.60
Bladder exstrophy	nr	nr	nr	nr
Polydactyly, preaxial	16	2	nr	7.76
Total Limb reduction defects (include unspecified)	107	2	3	48.28
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	23	nr	nr	9.92
Omphalocele	12	nr	1	5.60
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	13	nr	1	6.04
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)	33	nr	5	16.38
<20	nr	nr	1	2.54
20-24	2	nr	1	4.27
25-29	11	nr	nr	17.28
30-34	3	nr	1	10.43
35-39	3	nr	1	25.58
40-44	2	nr	1	75.57
45+	nr	nr	nr	nr
unknown	12	nr	nr	---

nr = not reported

Ireland
Dublin EUROCAT Registry

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

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

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

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

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

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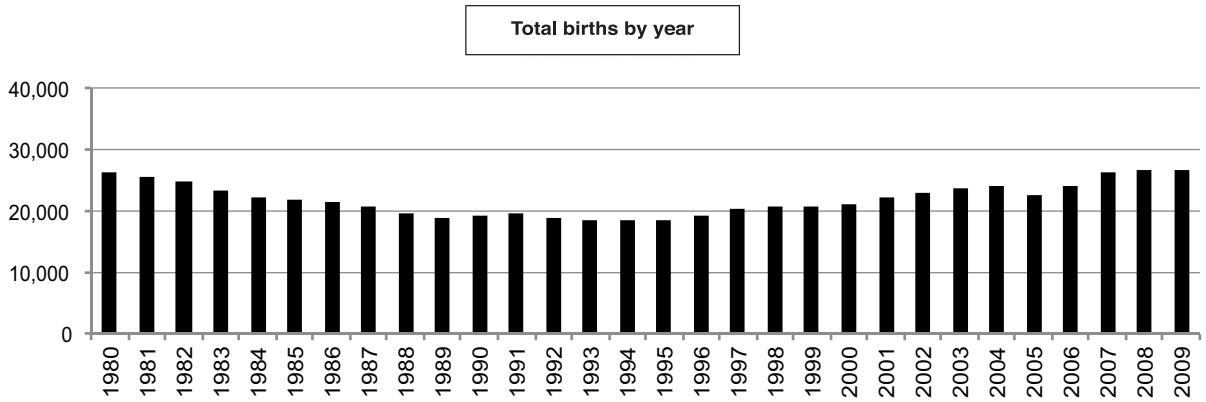
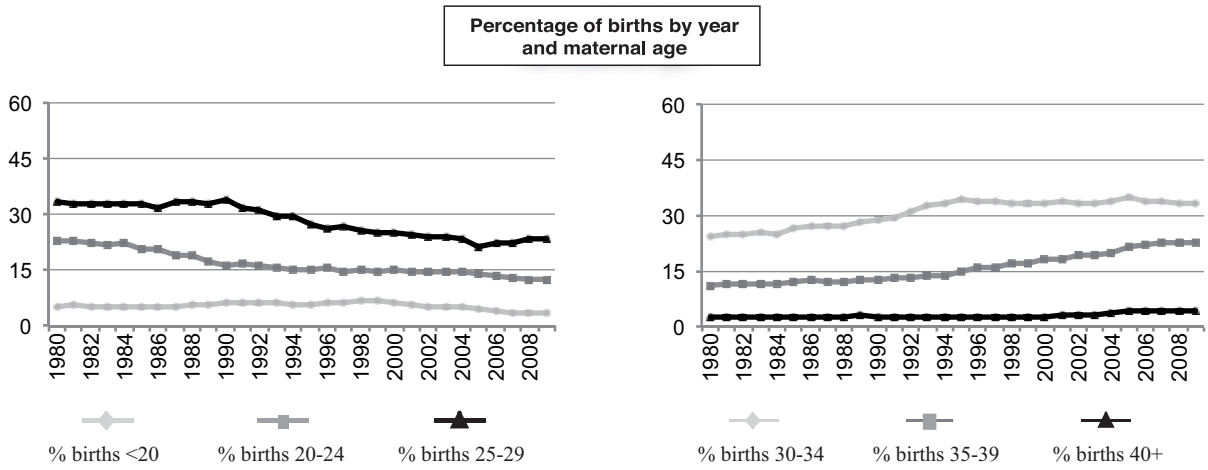
Ireland: Dublin





Ireland: Dublin, 2009

Live births (LB) (*)	26,502
Stillbirths (SB) (*)	120
Total births (*)	26,622
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	6	1		2.63
Spina bifida	10	0		3.76
Encephalocele	1	0		0.38
Microcephaly	3	0		1.13
Holoprosencephaly	0	1		0.38
Hydrocephaly	4	0		1.50
Anophthalmos	1	0		0.38
Microphthalmos	4	0		1.50
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	10	10		7.51
Tetralogy of Fallot	9	1		3.76
Hypoplastic left heart syndrome	8	1		3.38
Coarctation of aorta	17	1		6.76
Choanal atresia, bilateral	1	0		0.38
Cleft palate without cleft lip	17	1		6.76
Cleft lip with or without cleft palate	16	0		6.01
Oesophageal atresia/stenosis with or without fistula	9	1		3.76
Small intestine atresia/stenosis	1	0		0.38
Anorectal atresia/stenosis	12	0		4.51
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	15	0		5.63
Epispadias	nr	nr		nr
Indeterminate sex	3	2		1.88
Renal agenesis	3	1		1.50
Cystic kidney	9	2		4.13
Bladder exstrophy	1	0		0.38
Polydactyly, preaxial	25	1		9.77
Total Limb reduction defects (include unspecified)	8	0		3.01
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	5	1		2.25
Omphalocele	5	1		2.25
Gastroschisis	4	1		1.88
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	1	0		0.38
Trisomy 13	5	0		1.88
Trisomy 18	8	5		4.88
Down syndrome, all ages (include age unknown)	55	4		22.16
<20	0	0		0.00
20-24	2	0		6.02
25-29	4	0		6.43
30-34	13	2		17.00
35-39	29	2		51.15
40-44	7	0		64.75
45+	0	0		0.00
unknown	0	0		---

nr = not reported
(*) = estimate based on 2008 data

Ireland: Dublin, Previous years rates 1980 - 2009

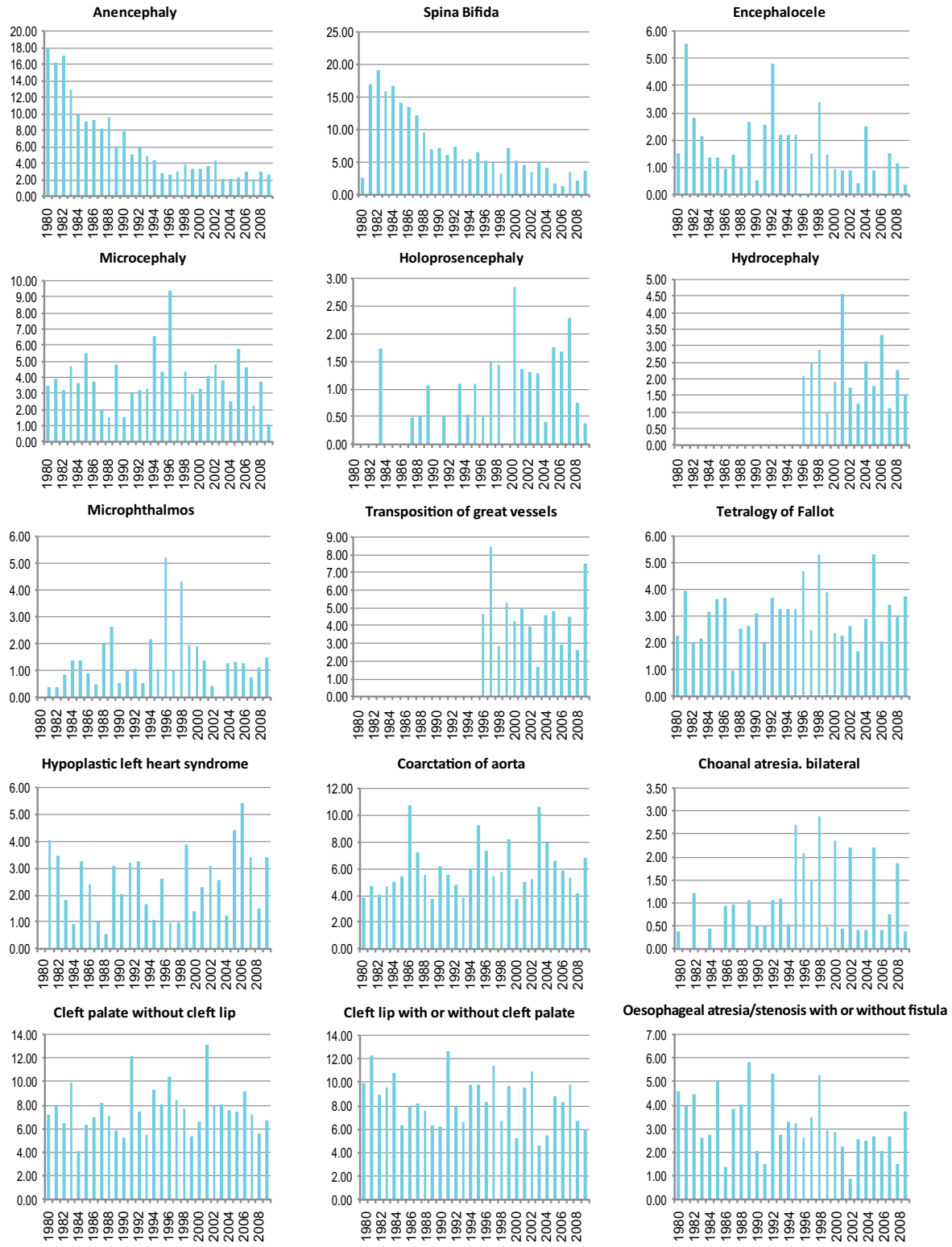
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**121,428**	**102,584**	**94,474**	**99,207**	**113,437**	**126,245**
Anencephaly		14.99	8.48	5.61	3.12	3.09	2.53
Spina bifida		14.08	11.41	6.35	5.44	4.50	2.53
Encephalocele		2.72	1.46	2.43	1.71	1.15	0.79
Microcephaly		3.79	3.51	3.49	4.54	3.70	3.41
Holoprosencephaly		0.33	0.39	0.42	0.91	1.41	1.35
Hydrocephaly		nr	nr	nr	2.10*	2.38	1.98
Anophthalmos		0.25	0.10	0.32	0.71	0.18	0.32
Microphthalmos		0.58	1.46	1.06	2.72	0.97	1.19
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.18	0.00
Anotia		nr	nr	nr	nr	0.14*	0.24
Microtia		nr	nr	nr	nr	0.00*	0.16
Unspecified Anotia/Microtia		nr	nr	nr	nr	0.00*	0.00
Transposition of great vessels		nr	nr	nr	5.32*	3.88	4.52
Tetralogy of Fallot		2.72	2.73	3.07	3.93	2.38	3.49
Hypoplastic left heart syndrome		2.31	1.66	2.65	1.92	2.12	3.56
Coarctation of aorta		4.45	6.63	5.29	7.16	6.61	5.70
Choanal atresia, bilateral		0.41	0.58	0.74	1.92	1.15	1.11
Cleft palate without cleft lip		7.16	6.92	7.94	7.96	8.64	7.21
Cleft lip with or without cleft palate		10.29	7.31	8.68	9.17	7.14	7.92
Oesophageal atresia/stenosis with or without fistula		3.71	4.00	2.96	3.53	2.20	2.53
Small intestine atresia/stenosis		2.55	3.02	2.12	2.12	1.23	1.11
Anorectal atresia/stenosis		3.46	3.80	3.07	2.42	2.38	3.88
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr
Hypospadias		15.24	10.04	12.70	18.35	14.02	10.54
Epispadias		nr	nr	nr	nr	nr	nr
Indeterminate sex		0.16	0.19	0.21	0.40	0.26	0.48
Renal agenesis		4.86	4.58	4.34	4.23	2.12	1.98
Cystic kidney		3.71	1.85	4.23	3.63	2.91	4.83
Bladder exstrophy		nr	nr	nr	0.62*	0.71	0.79
Polydactyly, preaxial		6.75	5.26	6.03	6.45	9.52	9.51
Total Limb reduction defects (include unspecified)		4.28	3.41	4.45	4.64	4.32	3.72
Transverse		nr	nr	nr	nr	nr	nr
Preaxial		nr	nr	nr	nr	nr	nr
Postaxial		nr	nr	nr	nr	nr	nr
Intercalary		nr	nr	nr	nr	nr	nr
Mixed		nr	nr	nr	nr	nr	nr
Unspecified		nr	nr	nr	nr	4.98*	3.41*
Diaphragmatic hernia		2.96	4.09	5.08	3.83	4.23	3.25
Omphalocele		2.72	2.63	1.69	2.52	3.79	2.38
Gastroschisis		0.16	0.58	0.85	2.02	3.17	2.61
Unspecified Omphalocele/Gastroschisis		0.00	0.00	0.00	0.00	0.00	0.00
Prune belly sequence		0.08	0.39	0.32	0.60	0.79	0.32
Trisomy 13		1.07	1.27	0.42	2.52	2.64	2.22
Trisomy 18		2.39	1.56	3.39	3.83	3.97	4.59
Down syndrome, all ages (include age unknown)		18.20	19.11	20.75	21.67	21.42	24.71
<20		nr	nr	17.58*	11.07	4.77	8.42
20-24		nr	nr	10.38*	7.41	6.59	9.15
25-29		nr	nr	10.23*	8.45	8.43	9.11
30-34		nr	nr	15.74*	19.50	13.26	20.30
35-39		nr	nr	44.06*	46.40	48.40	45.68
40-44		nr	nr	192.73*	128.88	141.70	94.12
45+		nr	nr	1153.85*	400.00	285.71	40.49
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

Ireland: Dublin

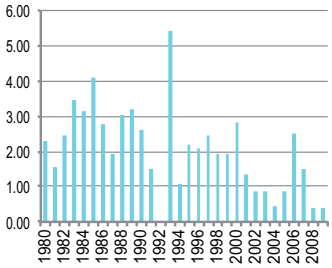
Time trends 1980-2009 (Birth prevalence rates per 10,000)



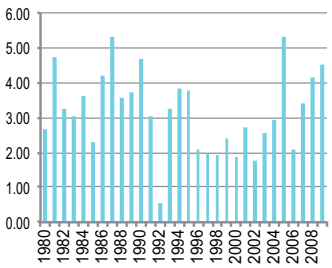
Note: L+S rates

Ireland: Dublin

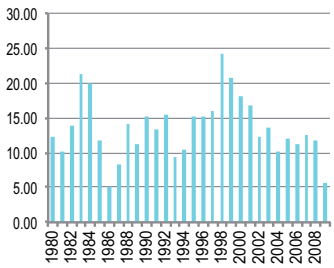
Small intestine atresia/stenosis



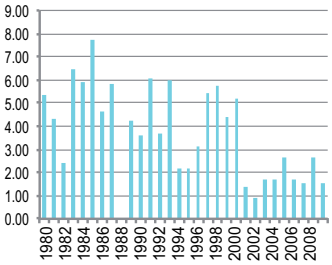
Anorectal atresia/stenosis



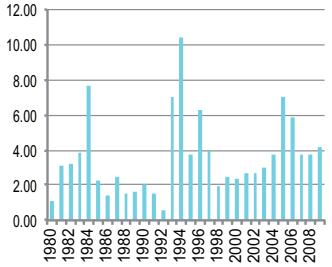
Hypospadias



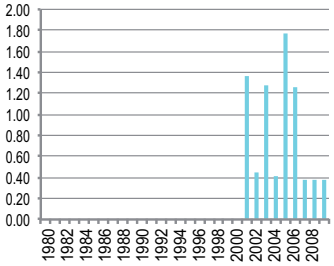
Renal agenesis



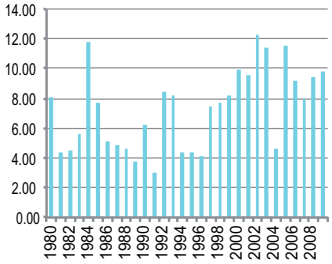
Cystic kidney



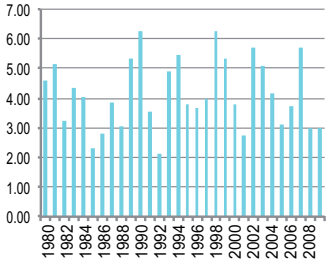
Bladder exstrophy



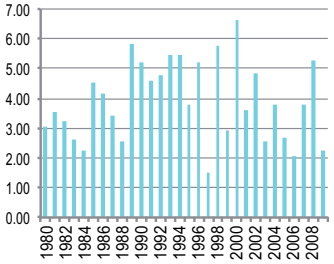
Polydactyly, preaxial



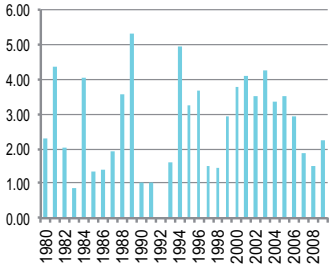
Limb reduction defects



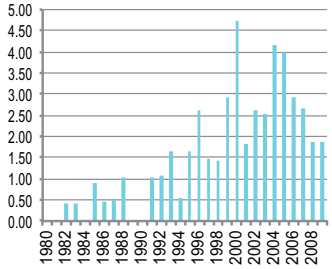
Diaphragmatic hernia



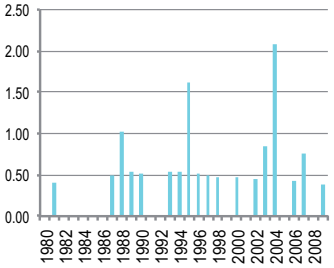
Omphalocele



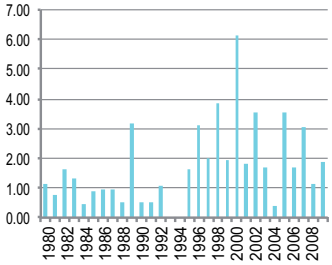
Gastroschisis



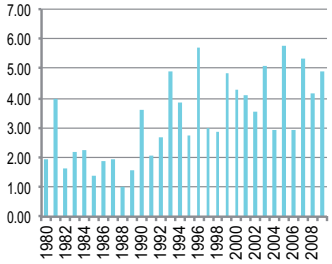
Prune belly sequence



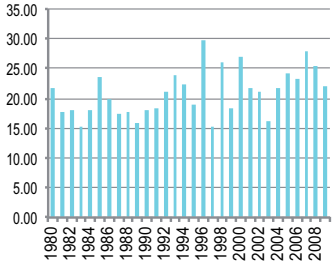
Trisomy 13



Trisomy 18

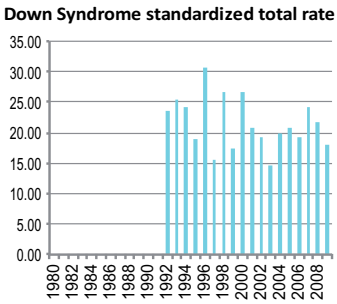


Down Syndrome



Note: L+S rates

Ireland: Dublin



Note: L+S rates

Israel: IBDSP

Israel Birth Defects Surveillance Program

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

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

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

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

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

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

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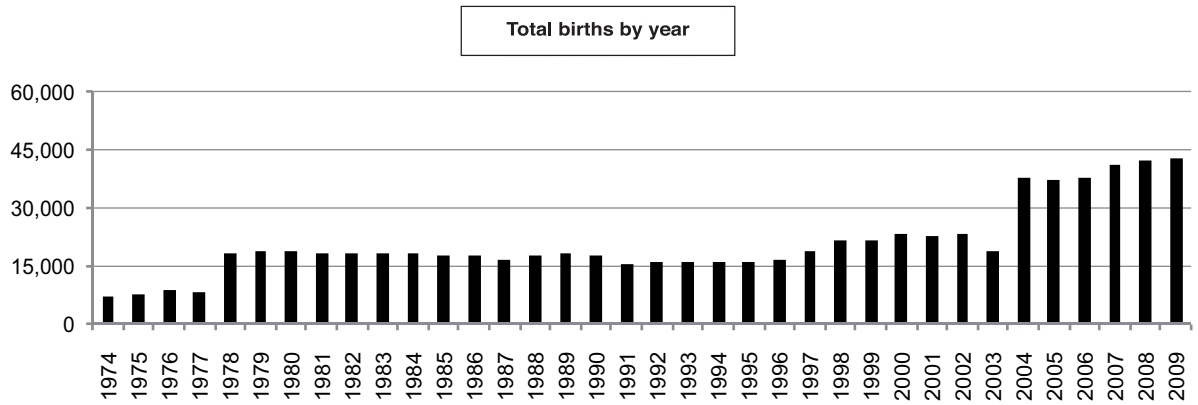
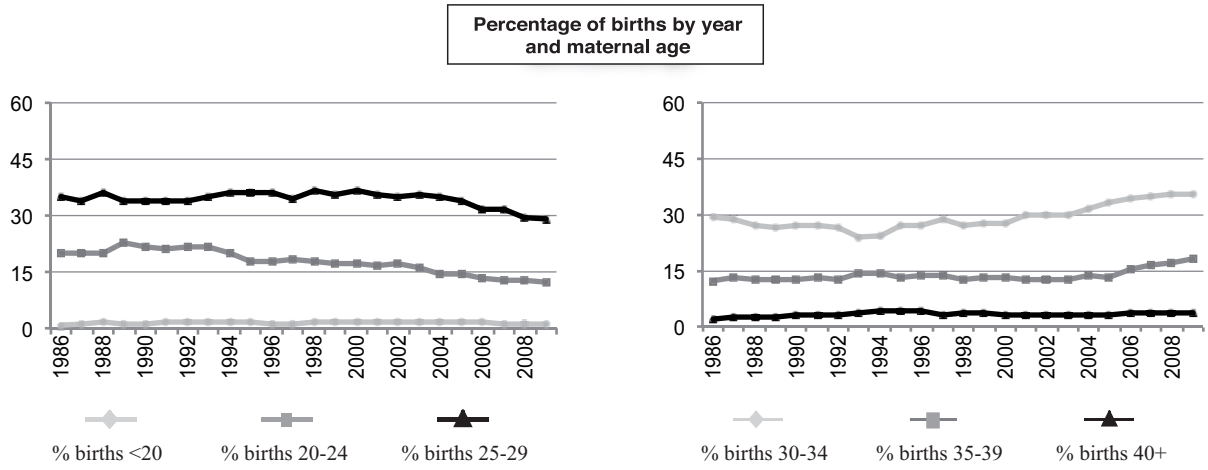
Israel: IBDSP





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	1	7.1	Cystic kidney	0	0.0
Spina bifida	8	21.6	Limb reduction defects	2	11.1
Encephalocele	1	14.3	Diaphragmatic hernia	0	0.0
Holoprosencephaly	2	50.0	Omphalocele	0	0.0
Hydrocephaly	12	22.6	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	1	4.8	Trisomy 13	0	0.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	1	14.3
Cleft lip with or without cleft palate	5	10.9	Down syndrome	15	16.5
Renal agenesis	1	20.0			

Total ToPs with births defects = 50 (Ratio ToPs/Births: 0.40 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Israel: IBDSP, 2009

Live births (LB)	42,608
Stillbirths (SB)	267
Total births	42,875
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	4	0	1.63
Spina bifida	12	0	1	3.03
Encephalocele	0	1	0	0.23
Microcephaly	13	1	0	3.27
Holoprosencephaly	2	0	0	0.47
Hydrocephaly	16	2	3	4.90
Anophthalmos	2	0	0	0.47
Microphthalmos	7	1	0	1.87
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.23
Microtia	7	0	0	1.63
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	9	0	0	2.10
Tetralogy of Fallot	11	0	0	2.57
Hypoplastic left heart syndrome	6	0	0	1.40
Coarctation of aorta	11	0	0	2.57
Choanal atresia, bilateral	1	0	0	0.23
Cleft palate without cleft lip	21	0	0	4.90
Cleft lip with or without cleft palate	12	0	1	3.03
Oesophageal atresia/stenosis with or without fistula	14	0	0	3.27
Small intestine atresia/stenosis	0	0	0	0.00
Anorectal atresia/stenosis	4	0	0	0.93
Undescended testis (36 weeks of gestation or later)	67	0	0	15.63
Hypospadias	150	0	0	34.99
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	0.23
Renal agenesis	2	0	0	0.47
Cystic kidney	9	0	0	2.10
Bladder exstrophy	2	0	0	0.47
Polydactyly, preaxial	1	0	0	0.23
Total Limb reduction defects (include unspecified)	9	0	1	2.33
Transverse	3	0	1	0.93
Preaxial	3	0	0	0.70
Postaxial	2	0	0	0.47
Intercalary	1	0	0	0.23
Mixed	0	0	0	0.00
Unspecified	0	0	0	0.00
Diaphragmatic hernia	6	0	0	1.40
Omphalocele	3	1	0	0.93
Gastroschisis	1	0	0	0.23
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	4	0	0	0.93
Trisomy 18	3	0	0	0.70
Down syndrome, all ages (include age unknown)	24	0	4	6.53
<20	0	0	0	0.00
20-24	3	0	0	5.64
25-29	3	0	1	3.20
30-34	3	0	0	1.98
35-39	7	0	2	11.49
40-44	7	0	1	57.97
45+	1	0	0	51.81
unknown	0	0	0	---

nr = not reported

Israel: IBDSP, Previous years rates 1974 - 2009

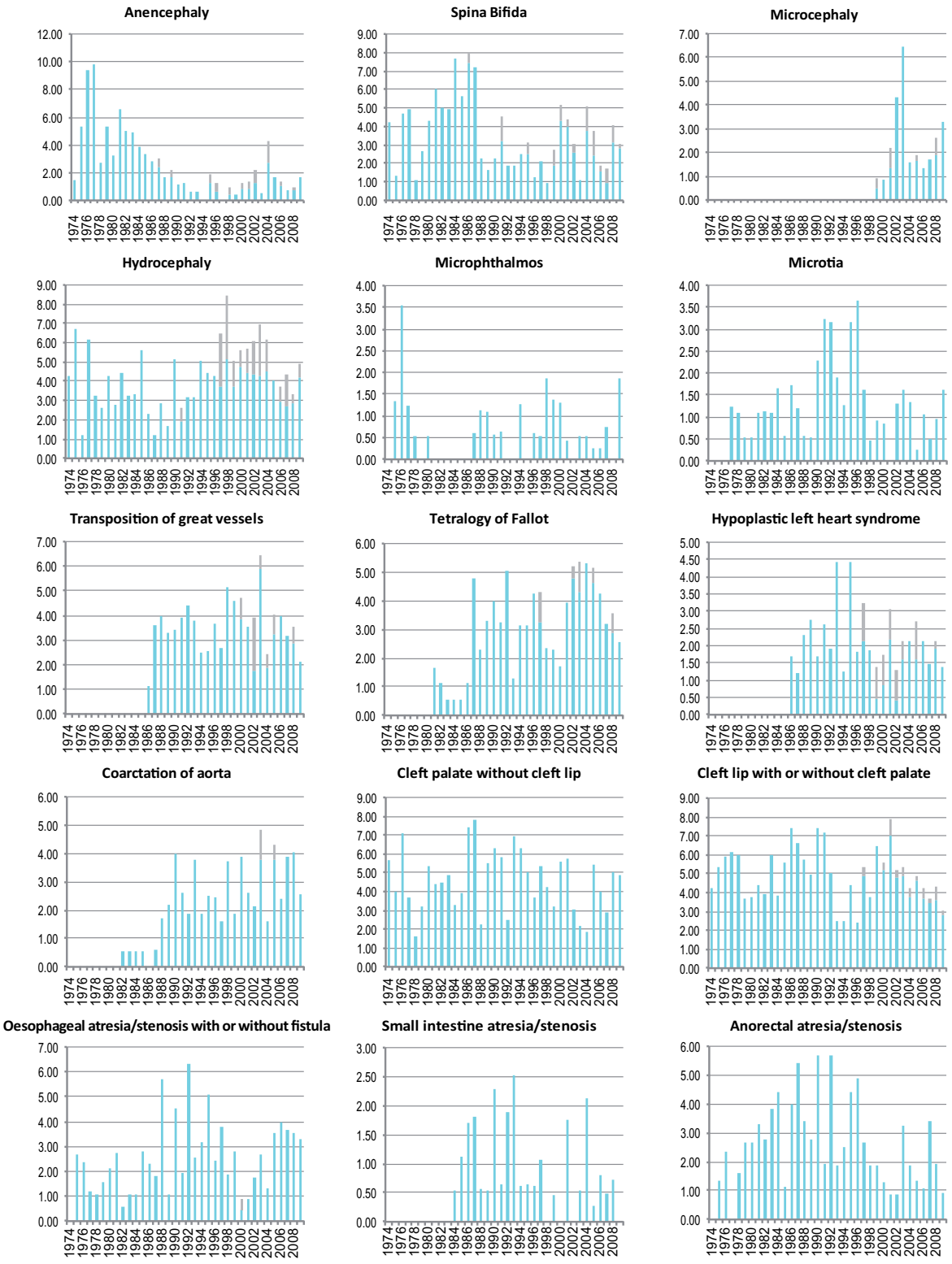
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**68,298**	**91,287**	**87,639**	**80,496**	**93,848**	**125,179**	**200,611**
Anencephaly	5.27	4.71	2.62	0.75	0.85	2.24	1.25
Spina bifida	2.78	5.59	4.91	2.61	2.02	3.99	2.89
Encephalocele	0.44	0.33	0.57	0.87	0.32	0.48	0.45
Microcephaly	nr	nr	0.00*	0.00	0.21	2.80	2.19
Holoprosencephaly	nr	0.00*	0.23	0.50	0.00	0.08	0.45
Hydrocephaly	3.66	3.61	2.74	3.85	5.86	6.07	4.09
Anophthalmos	0.00	0.00	0.00	0.00	0.00	0.16	0.15
Microphthalmos	0.88	0.11	0.57	0.50	0.96	0.56	0.65
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.00	0.00	0.00	0.12	0.00	0.00	0.05
Microtia	0.59	1.10	0.91	2.36	1.81	1.04	0.90
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	nr	3.01*	3.60	3.84	3.91	3.34
Tetralogy of Fallot	nr	0.77	2.40	3.35	3.20	4.39	3.69
Hypoplastic left heart syndrome	nr	nr	2.00*	2.36	2.45	2.08	1.94
Coarctation of aorta	nr	0.33	1.03	2.86	2.45	2.80	3.44
Choanal atresia, bilateral	nr	0.00*	0.34	0.25	0.11	0.16	0.10
Cleft palate without cleft lip	3.66	4.49	5.36	5.59	4.26	3.51	4.44
Cleft lip with or without cleft palate	5.12	4.38	6.05	4.97	4.58	5.51	3.99
Oesophageal atresia/stenosis with or without fistula	1.46	1.53	2.74	3.73	3.09	1.44	3.59
Small intestine atresia/stenosis	nr	0.55*	1.14	1.61	0.53	1.04	0.45
Anorectal atresia/stenosis	1.61	3.40	3.31	3.60	2.98	1.60	1.74
Undescended testis (36 weeks of gestation or later)	nr	nr	0.00*	0.00	0.00*	nr	15.63*
Hypospadias	29.14	26.73	30.24	43.85	34.52	37.63	34.35
Epispadias	0.15	0.00	0.11	0.25	0.11	0.32	0.10
Indeterminate sex	nr	nr	0.00*	0.00	0.00*	0.16*	0.24*
Renal agenesis	nr	nr	0.72	0.99	0.53	0.64	0.85
Cystic kidney	0.59	0.55	1.48	0.99	1.49	2.08	2.29
Bladder exstrophy	0.15	0.22	0.68	0.37	0.32	0.24	0.50
Polydactyly, preaxial	0.29	0.66	0.46	0.37	1.07	0.96	0.75
Total Limb reduction defects (include unspecified)	3.51	2.85	2.51	3.60	1.60	2.16	1.74
Transverse	nr	0.55*	1.03	1.99	0.43	0.88	0.90
Preaxial	nr	0.55*	0.68	0.12	0.75	0.96	0.35
Postaxial	nr	0.55*	0.11	0.37	0.32	0.08	0.15
Intercalary	nr	0.55*	0.34	0.25	0.11	0.16	0.25
Mixed	nr	0.55*	0.34	0.87	0.00	0.08	0.10
Unspecified	nr	0.00*	0.00	0.00	0.00	0.00	0.00
Diaphragmatic hernia	2.15*	2.52	1.83	2.98	1.49	1.92	1.69
Omphalocele	1.90	2.52	0.80	1.12	0.43	0.88	0.85
Gastroschisis	0.00*	0.44	0.57	0.00	0.11	0.40	0.25
Unspecified Omphalocele/Gastroschisis	0.00*	0.00	0.00	0.00	0.11	0.08	0.00
Prune belly sequence	0.44	0.22	0.00	0.12	0.11	0.08	0.20
Trisomy 13	nr	1.10*	0.34	0.50	0.32	0.56	0.40
Trisomy 18	nr	0.55*	0.80	0.50	0.85	1.52	0.65
Down syndrome, all ages (include age unknown)	11.27	9.64	12.32	7.58	8.31	10.39	7.78
<20	nr	nr	nr	0.00*	0.00	13.27	3.80
20-24	nr	nr	nr	0.00*	2.37	3.95	4.52
25-29	nr	nr	nr	2.74*	5.06	5.38	3.37
30-34	nr	nr	nr	7.50*	6.57	7.73	4.17
35-39	nr	nr	nr	15.27*	14.50	22.07	14.13
40-44	nr	nr	nr	39.76*	56.84	70.98	68.19
45+	nr	nr	nr	57.80*	99.26	121.95	64.68
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years or 6 years

Israel: IBDSP

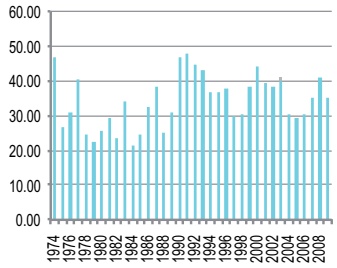
Time trends 1974-2009 (Birth prevalence rates per 10,000)



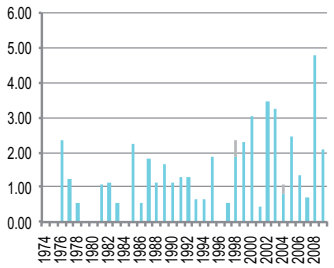
Note: L+S rates, ToP rates

Israel: IBDSP

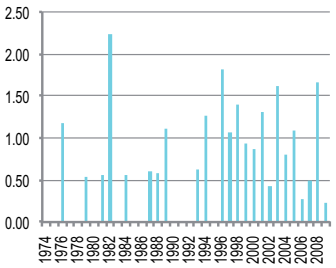
Hypospadias



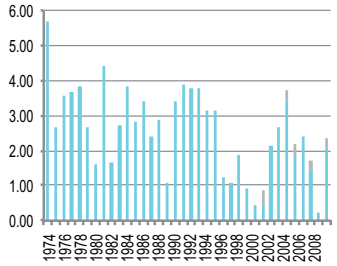
Cystic kidney



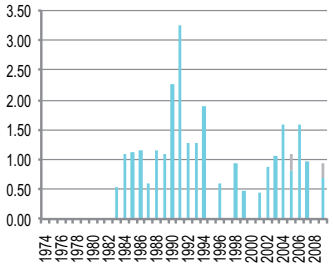
Polydactyly, preaxial



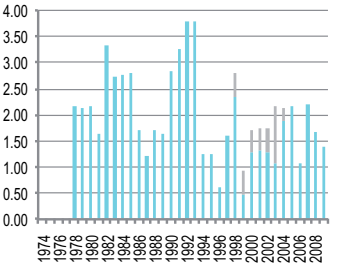
Limb reduction defects



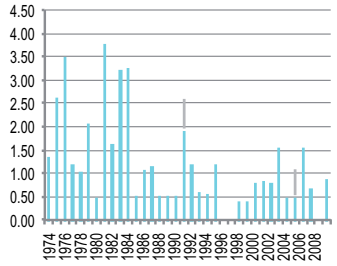
Limb reduction defects - transverse



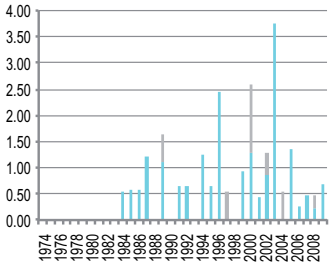
Diaphragmatic hernia



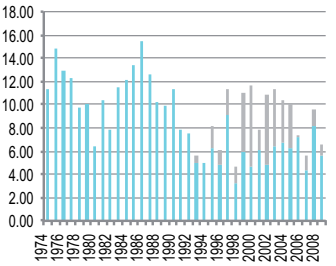
Omphalocele



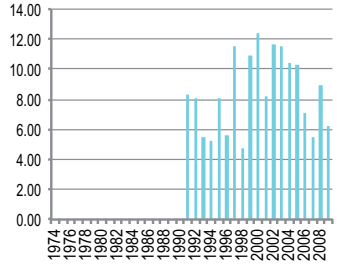
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Italy - Campania: BDRCam
Birth Defects Registry of Campania

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

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

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

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

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

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

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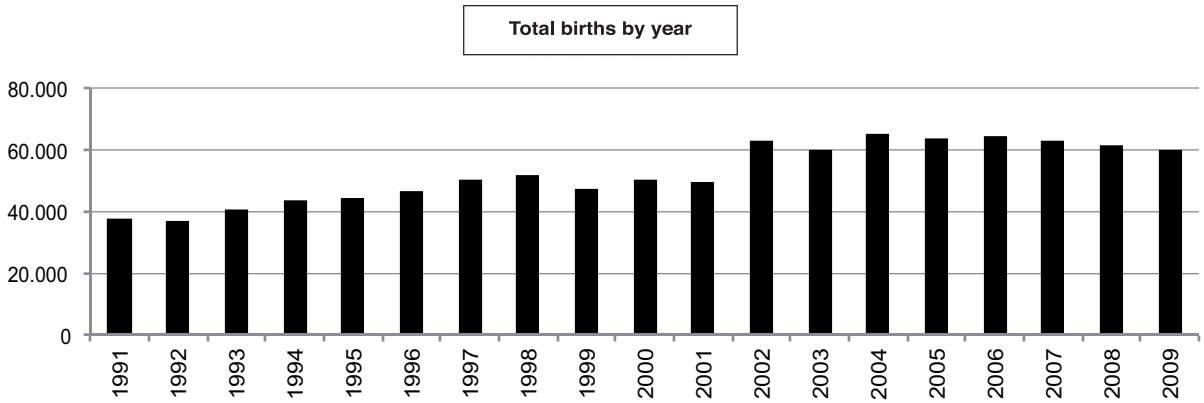
E-mail: giorecam@tin.it

Italy: BDRCam



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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	55	87.3	Cystic kidney	5	5.0
Spina bifida	30	54.5	Limb reduction defects	13	17.6
Encephalocele	9	56.3	Diaphragmatic hernia	7	16.7
Holoprosencephaly	16	32.7	Omphalocele	11	52.4
Hydrocephaly	63	42.9	Gastroschisis	6	75.0
Hypoplastic left heart syndrome	32	66.7	Trisomy 13	6	60.0
Cleft palate without cleft lip	2	1.9	Trisomy 18	24	66.7
Cleft lip with or without cleft palate	12	10.8	Down syndrome	222	53.9
Renal agenesis	18	11.8			

Total ToPs with births defects = 829 (Ratio ToPs/Births: 4.50 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: BDRCam, 2009

Live births (LB)	59,505
Stillbirths (SB)	192
Total births	59,697
Number of terminations of pregnancy (ToP) for birth defects	331

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	2	25	4.52
Spina bifida	10	0	9	3.18
Encephalocele	2	0	2	0.67
Microcephaly	13	0	0	2.18
Holoprosencephaly	3	0	2	0.84
Hydrocephaly	24	0	17	6.87
Anophthalmos	1	0	0	0.17
Microphthalmos	8	0	0	1.34
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	5	0	0	0.84
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	0	1	1.17
Tetralogy of Fallot	24	0	2	4.36
Hypoplastic left heart syndrome	7	0	11	3.02
Coarctation of aorta	47	0	0	7.87
Choanal atresia, bilateral	5	0	0	0.84
Cleft palate without cleft lip	42	0	0	7.04
Cleft lip with or without cleft palate	35	0	5	6.70
Oesophageal atresia/stenosis with or without fistula	21	0	2	3.85
Small intestine atresia/stenosis	17	0	0	2.85
Anorectal atresia/stenosis	14	0	0	2.35
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	6	0	0	1.01
Epispadias	1	0	0	0.17
Indeterminate sex	5	0	1	1.01
Renal agenesis	37	0	3	6.70
Cystic kidney	22	0	2	4.02
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	8	0	0	1.34
Total Limb reduction defects (include unspecified)	20	0	9	4.86
Transverse	8	0	3	1.84
Preaxial	3	0	3	1.01
Postaxial	1	0	0	0.17
Intercalary	1	0	1	0.34
Mixed	3	0	0	0.50
Unspecified	4	0	2	1.01
Diaphragmatic hernia	6	0	5	1.84
Omphalocele	1	0	5	1.01
Gastroschisis	2	0	1	0.50
Unspecified Omphalocele/Gastroschisis	5	0	0	0.84
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	1	0.50
Trisomy 18	4	0	5	1.51
Down syndrome, all ages (include age unknown)	66	0	86	25.46
<20	0	0	0	0.00
20-24	1	0	3	3.93
25-29	3	0	2	3.98
30-34	5	0	21	13.68
35-39	8	0	30	34.93
40-44	7	0	30	151.64
45+	0	0	0	0.00
unknown	42	0	0	---

nr = not reported

Italy-Campania: BDRCam, previous years rates 1991-2009

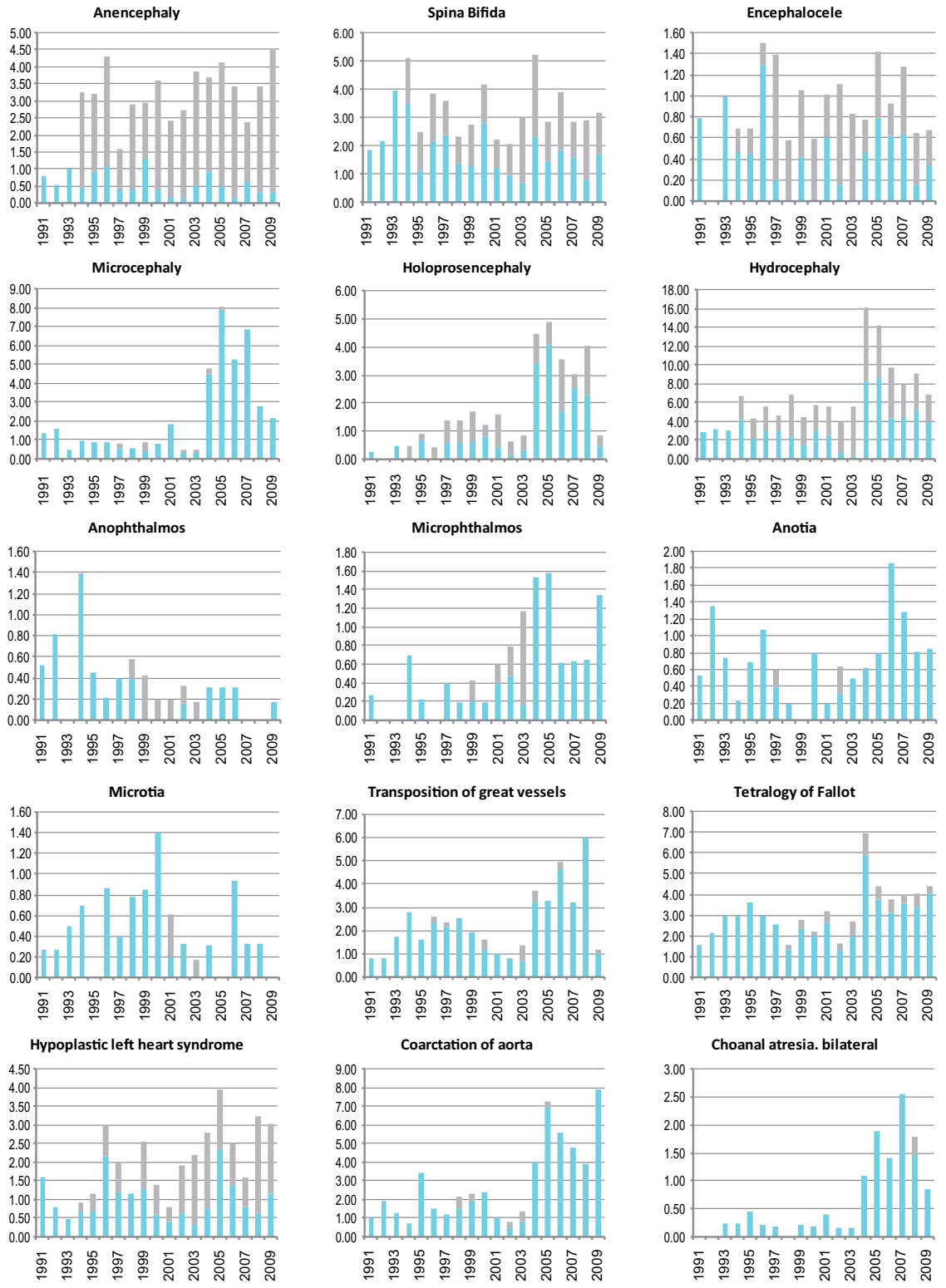
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-19891990-1994*	1995-1999	2000-2004	2005-2009
Total births			**158,531**	**240,032**	**287,484**	**311,687**
Anencephaly			1.45	2.96	3.27	3.56
Spina bifida			3.34	3.00	3.37	3.14
Encephalocele			0.63	1.04	0.87	0.99
Microcephaly			1.07	0.79	1.74	5.07
Holoprosencephaly			0.32	1.17	1.81	3.30
Hydrocephaly			4.04	5.17	7.65	9.59
Anophthalmos			0.69	0.42	0.24	0.16
Microphthalmos			0.25	0.25	0.90	0.96
Unspecified Anophthalmos/Microphthalmos			0.00	0.00	0.00	0.42
Anotia			0.69	0.50	0.56	1.12
Microtia			0.44	0.58	0.52	0.32
Unspecified Anotia/Microtia			0.00	0.00	0.03	0.19
Transposition of great vessels			1.58	2.21	1.74	3.75
Tetralogy of Fallot			2.46	2.67	3.41	4.11
Hypoplastic left heart syndrome			0.95	1.96	1.88	2.86
Coarctation of aorta			1.20	2.08	1.95	5.87
Choanal atresia, bilateral			0.13	0.21	0.42	1.70
Cleft palate without cleft lip			4.73	4.29	5.01	6.10
Cleft lip with or without cleft palate			6.81	7.17	6.61	6.64
Oesophageal atresia/stenosis with or without fistula			2.33	2.25	2.09	3.75
Small intestine atresia/stenosis			1.83	2.17	2.26	3.24
Anorectal atresia/stenosis			2.84	3.04	3.30	3.85
Undescended testis (36 weeks of gestation or later)			nr	nr	nr	nr
Hypospadias			3.66	2.79	5.67	2.57
Epispadias			0.25	0.21	0.21	0.42
Indeterminate sex			0.25	0.67	0.87	0.87
Renal agenesis			1.32	3.25	5.11	7.76
Cystic kidney			1.64	2.71	3.30	6.22
Bladder exstrophy			0.19	0.33	0.14	0.22
Polydactyly, preaxial			1.77	1.75	3.44	5.65
Total Limb reduction defects (include unspecified)			5.30	4.79	4.97	4.20
Transverse			3.78	2.42	2.68	2.57
Preaxial			0.63	0.92	0.80	0.77
Postaxial			0.25	0.54	0.52	0.39
Intercalary			0.32	0.46	0.35	0.16
Mixed			0.19	0.12	0.03	0.19
Unspecified			0.00	0.00	0.07	0.22
Diaphragmatic hernia			1.77	2.29	2.78	2.95
Omphalocele			1.32	2.00	2.05	1.48
Gastroschisis			0.32	0.62	0.59	0.26
Unspecified Omphalocele/Gastroschisis			0.00	0.00	0.03	0.19
Prune belly sequence			0.00	0.10	0.08	0.26
Trisomy 13			0.82	0.71	0.66	0.77
Trisomy 18			0.76	1.79	1.81	2.50
Down syndrome, all ages (include age unknown)			12.05	13.71	13.77	21.24
<20			4.80	3.52	4.45	0.00*
20-24			6.48	4.46	2.18	3.93*
25-29			7.35	6.02	5.33	3.98*
30-34			13.47	11.00	6.25	13.67*
35-39			38.39	31.86	27.34	34.93*
40-44			72.76	140.29	89.33	151.64*
45+			185.19	232.56	202.90	0.00*
unknown			---	---	---	---

nr = not reported
* data include less than 5 years

Italy-Campania: BDRCam

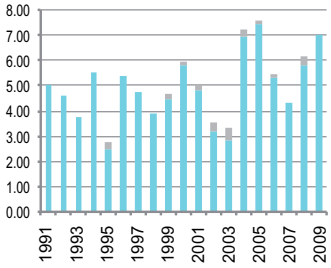
Time trends 1991-2009 (Birth prevalence rates per 10,000)



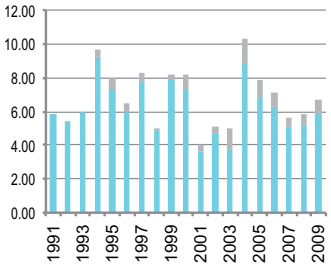
Note: L+S rates, ToP rates

Italy-Campania: BDRCam

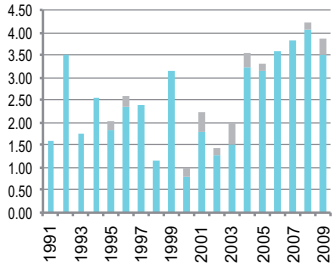
Cleft palate without cleft lip



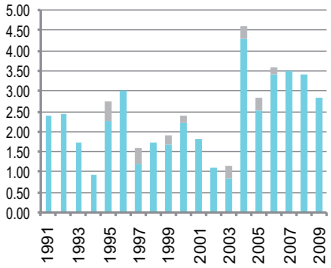
Cleft lip with or without cleft palate



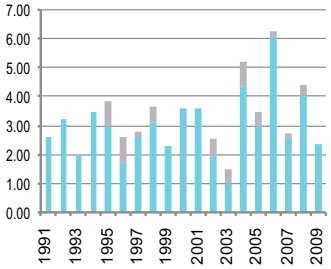
Oesophageal atresia/stenosis with or without fistula



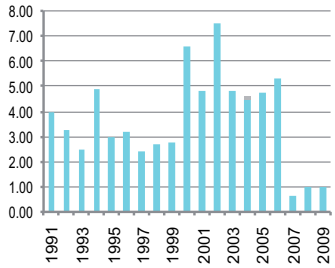
Small intestine atresia/stenosis



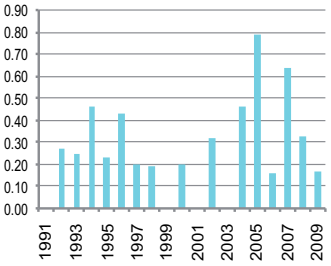
Anorectal atresia/stenosis



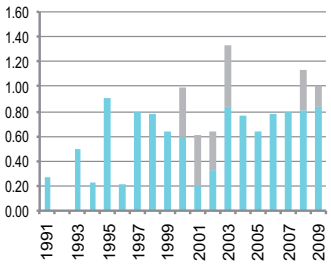
Hypospadias



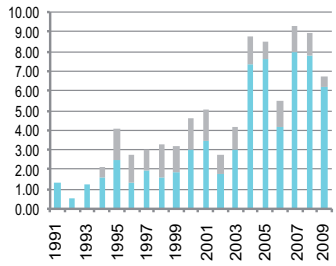
Epispadias



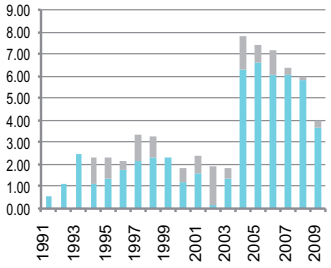
Indeterminate sex



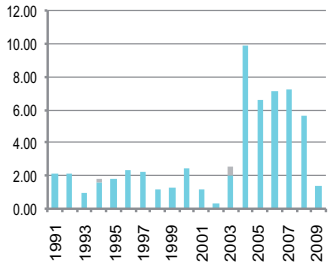
Renal agenesis



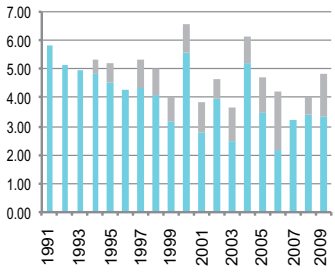
Cystic kidney



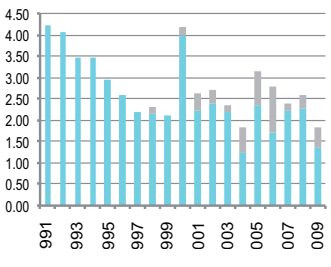
Polydactyly, preaxial



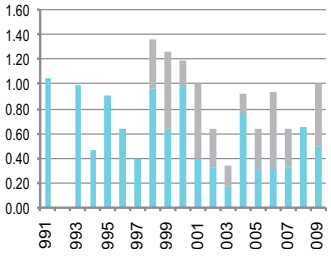
Limb reduction defects



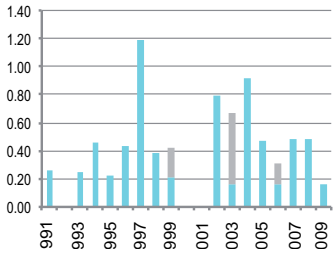
Limb reduction defects - transverse



Limb reduction defects - preaxial

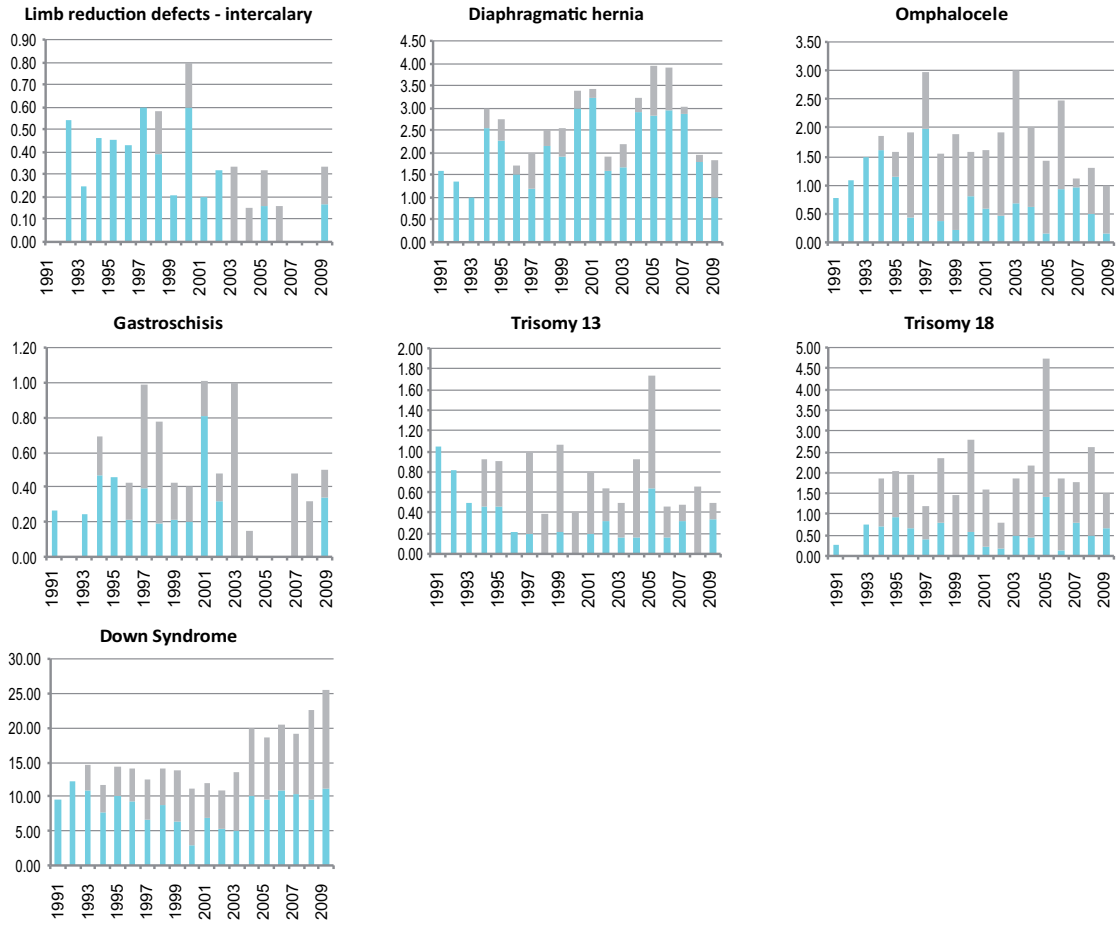


Limb reduction defects - postaxial



Note: L+S rates, ToP rates

Italy-Campania: BDRCam



Note: L+S rates, ToP rates

Italy - Emilia Romagna: IMER

Emilia Romagna Registry of Congenital Malformations

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

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

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

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

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

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

Addresses and Staff:
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Centro per lo Studio delle Malformazioni Congenite
e Centro Malattie Rare
U.O. Neonatologia
Universita' di Bologna
Via Massarenti 11
40138 Bologna, Italy

Phone: 39-051-342754 /6364654
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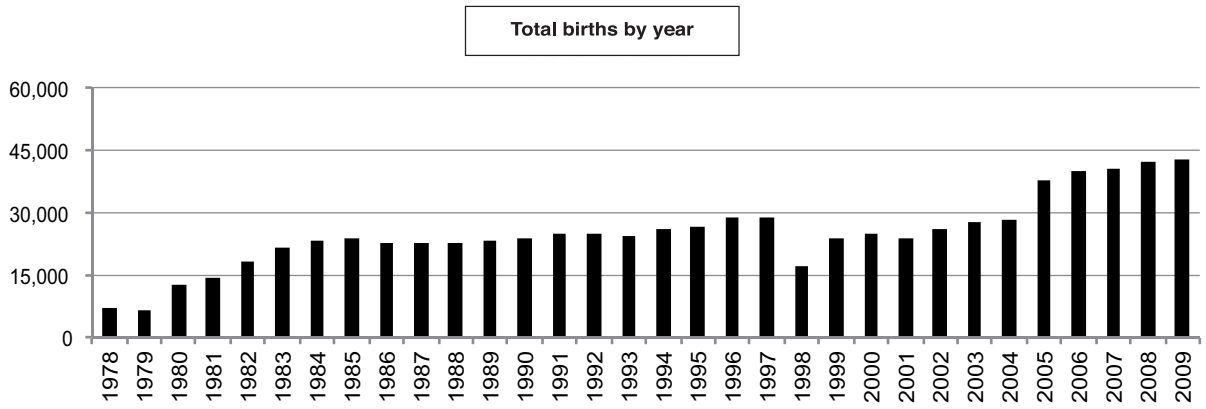
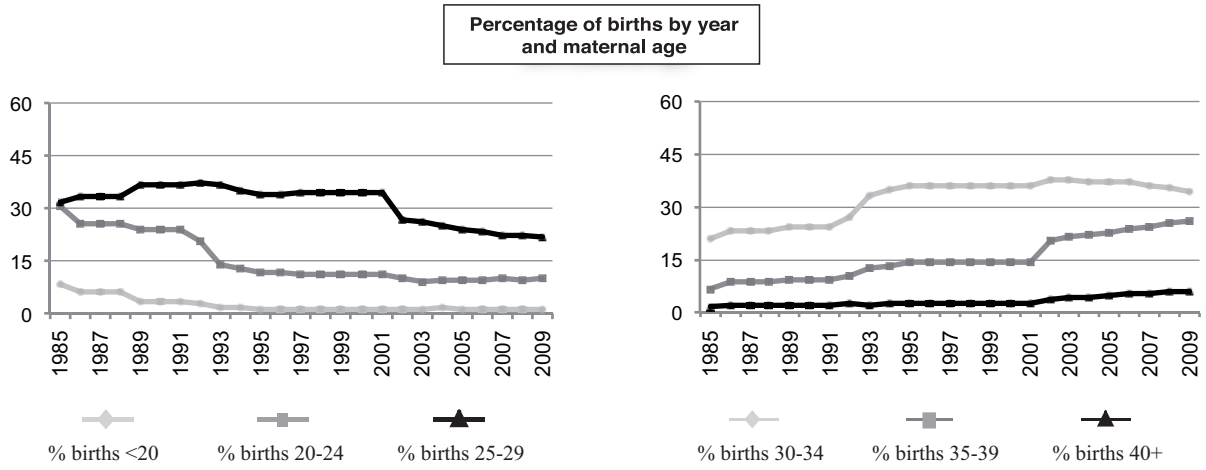
E-mail: guido.cocchi@unibo.it

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

Italy: IMER





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	23	79.3	Cystic kidney	14	27.5
Spina bifida	22	64.7	Limb reduction defects	14	29.2
Encephalocele	6	60.0	Diaphragmatic hernia	5	13.2
Holoprosencephaly	10	76.9	Omphalocele	16	55.2
Hydrocephaly	30	63.8	Gastroschisis	2	20.0
Hypoplastic left heart syndrome	15	53.6	Trisomy 13	19	95.0
Cleft palate without cleft lip	4	6.3	Trisomy 18	39	81.3
Cleft lip with or without cleft palate	14	15.6	Down syndrome	182	70.0
Renal agenesis	12	27.9			

Total ToPs with births defects = 405 (Ratio ToPs/Births: 3.22 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: IMER, 2009

Live births (LB)	42,665
Stillbirths (SB)	107
Total births	42,772
Number of terminations of pregnancy (ToP) for birth defects	194

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	2	7	2.34
Spina bifida	6	1	9	3.74
Encephalocele	3	0	0	0.70
Microcephaly	6	0	1	1.64
Holoprosencephaly	0	0	1	0.23
Hydrocephaly	7	0	4	2.57
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	1	0.70
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.23
Microtia	3	0	0	0.70
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	16	0	1	3.97
Tetralogy of Fallot	15	0	2	3.97
Hypoplastic left heart syndrome	5	0	5	2.34
Coarctation of aorta	15	0	1	3.74
Choanal atresia, bilateral	2	0	0	0.47
Cleft palate without cleft lip	20	0	0	4.68
Cleft lip with or without cleft palate	28	2	3	7.72
Oesophageal atresia/stenosis with or without fistula	15	0	1	3.74
Small intestine atresia/stenosis	21	0	0	4.91
Anorectal atresia/stenosis	4	0	1	1.17
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	61	0	2	14.73
Epispadias	2	0	0	0.47
Indeterminate sex	0	0	1	0.23
Renal agenesis	6	0	1	1.64
Cystic kidney	12	0	1	3.04
Bladder exstrophy	3	0	0	0.70
Polydactyly, preaxial	8	0	0	1.87
Total Limb reduction defects (include unspecified)	7	0	2	2.10
Transverse	4	0	2	1.40
Preaxial	2	0	0	0.47
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	1	0	0	0.23
Diaphragmatic hernia	12	0	1	3.04
Omphalocele	7	0	5	2.81
Gastroschisis	2	0	0	0.47
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	4	0.94
Trisomy 18	2	0	15	3.97
Down syndrome, all ages (include age unknown)	29	0	68	22.68
<20	0	0	0	0.00
20-24	1	0	1	4.64
25-29	2	0	2	4.31
30-34	6	0	8	9.58
35-39	12	0	32	40.25
40-44	6	0	22	112.63
45+	0	0	2	166.67
unknown	2	0	1	---

nr = not reported

Italy: IMER, Previous years rates 1978 - 2009

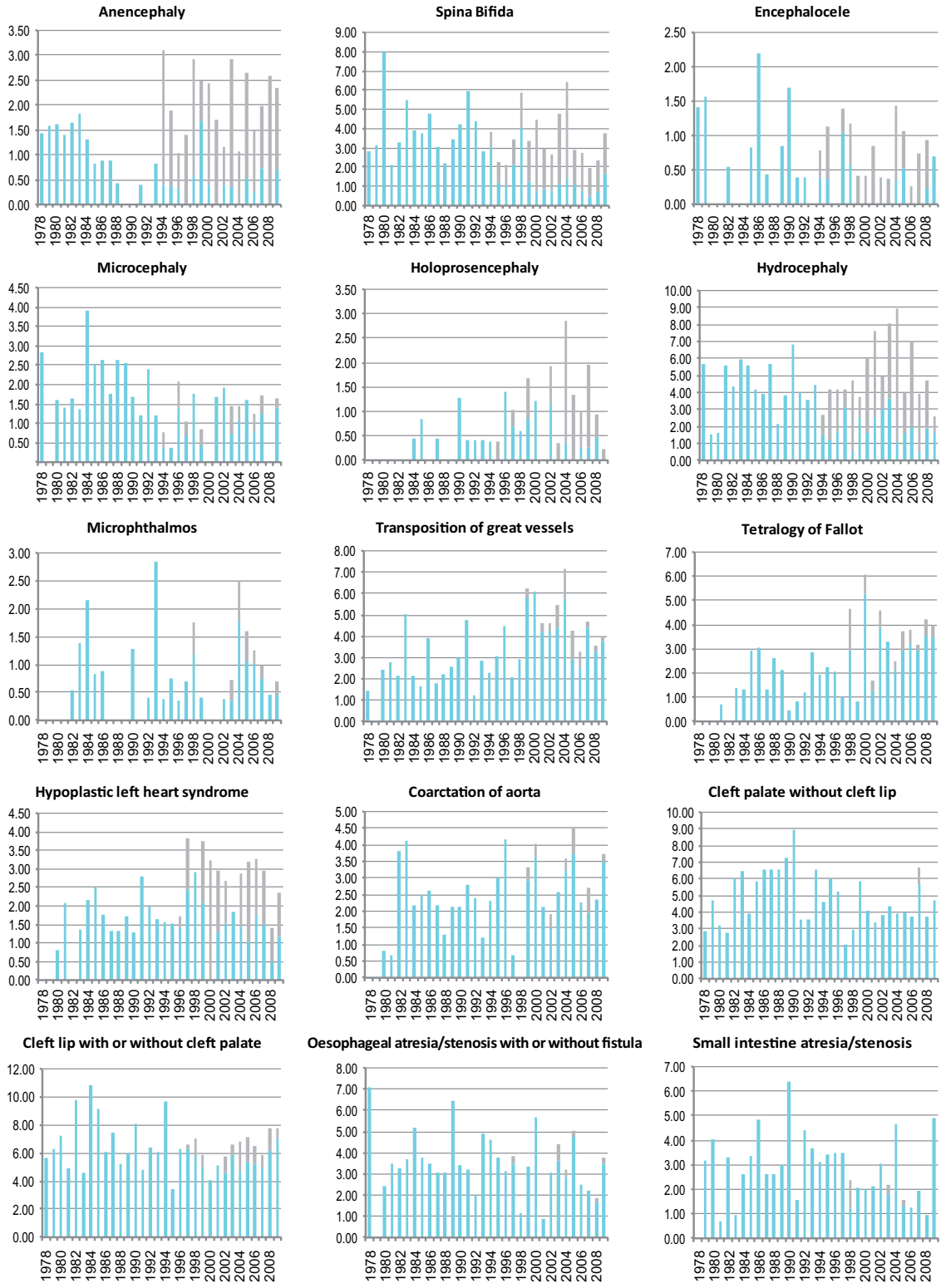
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979*	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**13,407**	**90,081**	**115,805**	**124,129**	**125,188**	**129,766**	**203,283**
Anencephaly	1.49	1.55	0.60	0.89	1.84	1.85	2.21
Spina bifida	2.98	4.44	3.45	4.27	3.20	4.32	2.75
Encephalocele	1.49	0.11	0.86	0.64	0.80	0.69	0.74
Microcephaly	1.49	2.11	2.42	1.45	1.20	1.31	1.23
Holoprosencephaly	0.00	0.11	0.26	0.56	1.04	1.31	1.08
Hydrocephaly	3.73	4.88	3.97	4.27	4.15	7.17	4.43
Anophthalmos	0.75	0.33	0.00	0.16	0.40	0.39	0.00
Microphthalmos	0.00	1.00	0.35	0.97	0.72	0.77	0.98
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.15
Anotia	nr	nr	nr	1.54*	0.40	0.85	0.79
Microtia	nr	nr	nr	1.16*	0.64	0.46	0.79
Unspecified Anotia/Microtia	nr	nr	nr	0.00*	0.00	0.00	0.00
Transposition of great vessels	0.75	3.00	2.42	2.82	3.75	5.63	3.94
Tetralogy of Fallot	nr	0.78	2.42	1.45	2.00	3.62	3.79
Hypoplastic left heart syndrome	0.00	1.33	1.73	1.85	2.72	2.70	2.61
Coarctation of aorta	nr	2.55	2.16	2.18	2.40	2.85	3.10
Choanal atresia, bilateral	0.00	0.22	0.26	0.32	0.08	0.46	0.34
Cleft palate without cleft lip	3.73	4.66	6.56	5.40	4.47	3.93	4.57
Cleft lip with or without cleft palate	5.97	7.66	6.82	7.01	5.75	5.70	7.03
Oesophageal atresia/stenosis with or without fistula	3.73	3.77	3.97	3.63	3.20	3.47	3.05
Small intestine atresia/stenosis	1.49	2.22	3.28	3.79	3.04	2.85	2.16
Anorectal atresia/stenosis	0.75	3.55	2.68	3.14	2.24	4.16	1.72
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	12.68	20.20	20.38	18.12	16.09	16.95	14.76
Epispadias	nr	nr	nr	nr	0.00	0.00	0.10
Indeterminate sex	nr	nr	nr	nr	0.16	0.39	0.49
Renal agenesis	4.48	1.00	1.64	1.45	2.48	4.39	3.54
Cystic kidney	0.75	0.33	1.04	0.24	3.91	3.62	4.13
Bladder exstrophy	0.75	0.33	0.78	0.08	0.16	0.23	0.34
Polydactyly, preaxial	8.95	8.66	8.29	7.41	3.59	2.31	3.00
Total Limb reduction defects (include unspecified)	nr	nr	5.53	5.64	3.99	4.70	4.62
Transverse	nr	nr	3.28	2.82	1.92	1.62	1.91*
Preaxial	nr	nr	0.52	0.97	0.88	0.92	1.08*
Postaxial	nr	nr	0.69	0.48	0.40	0.69	0.25*
Intercalary	nr	nr	0.52	0.73	0.48	0.62	0.17*
Mixed	nr	nr	0.26	0.48	0.08	0.15	0.17*
Unspecified	nr	nr	0.26	0.16	0.24	0.69	1.00*
Diaphragmatic hernia	0.00	1.67	1.81	3.38	2.80	4.08	2.80
Omphalocele	2.24	1.33	2.25	2.18	1.28	3.08	1.87
Gastroschisis	0.00	1.00	0.69	1.05	0.48	1.39	0.89
Unspecified Omphalocele/Gastroschisis	0.00	0.33	0.95	0.56	0.00	0.00	0.00
Prune belly sequence	0.00	0.33	0.43	0.24	0.40	0.23	0.05
Trisomy 13	0.75	1.55	0.78	0.73	0.96	1.93	1.33
Trisomy 18	0.75	1.55	0.78	0.89	2.16	4.93	4.23
Down syndrome, all ages (include age unknown)	21.63	13.32	13.30	13.45	19.73	18.73	19.73
<20	nr	nr	1.40	8.59	12.63	5.57	13.03
20-24	nr	nr	4.89	5.97	8.30	7.49	4.02
25-29	nr	nr	10.97	7.71	7.70	5.30	5.25
30-34	nr	nr	15.77	13.98	13.74	11.48	9.94
35-39	nr	nr	35.62	31.95	43.16	39.00	36.75
40-44	nr	nr	71.70	79.17	177.78	112.31	89.31
45+	nr	nr	52.36	158.73	135.14	181.82	117.19
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years or 6 years

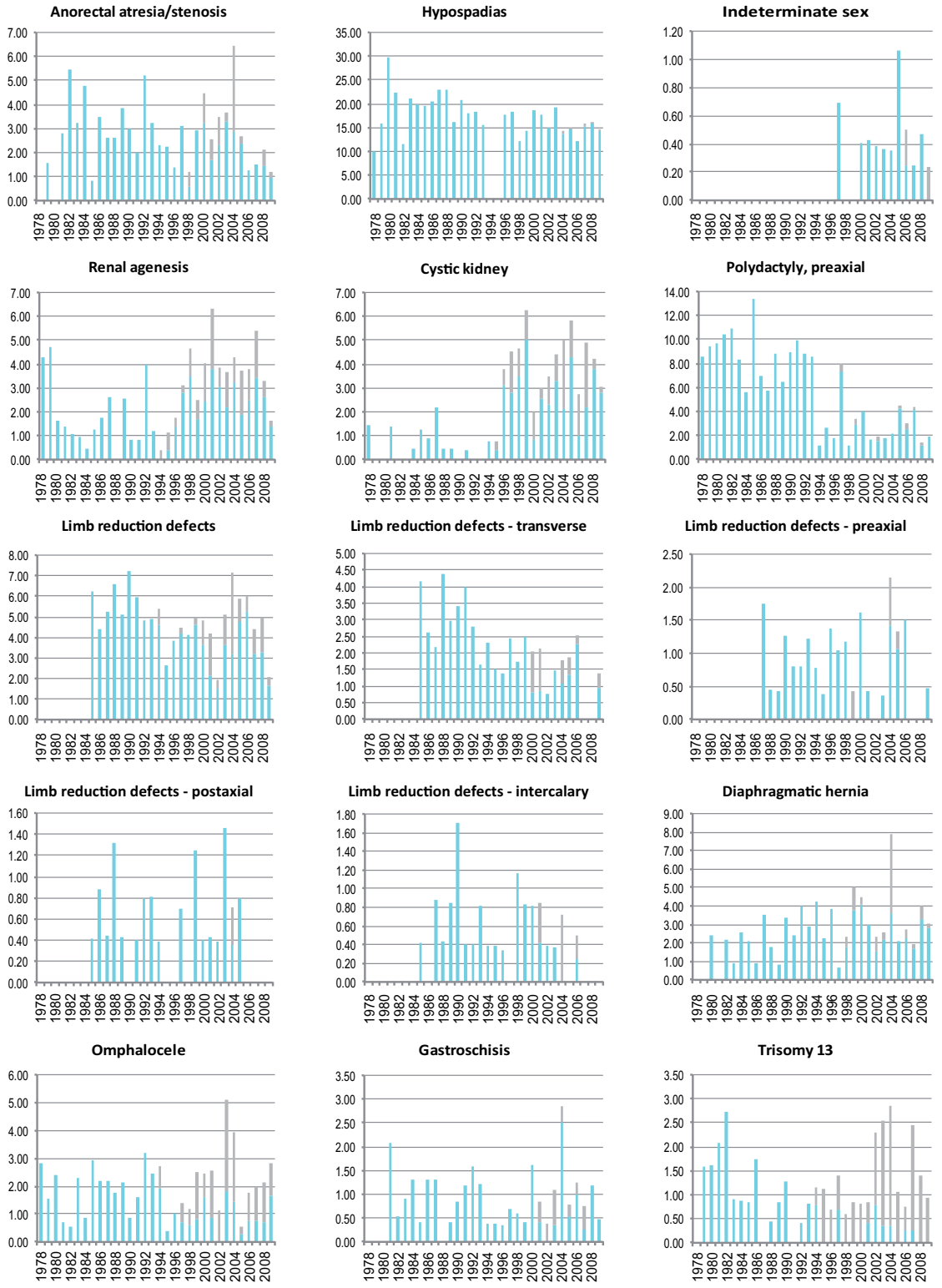
Italy: IMER

Time trends 1978-2009 (Birth prevalence rates per 10,000)



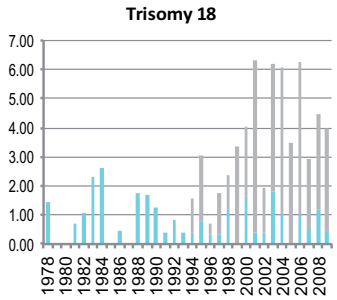
Note: L+S rates, ToP rates

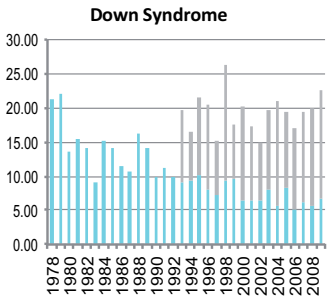
Italy: IMER

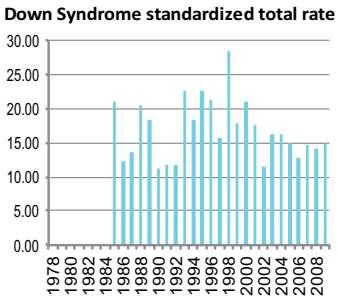


Note: L+S rates, ToP rates

Italy: IMER







Note: L+S rates, ToP rates

ITALY-Lombardy: CMRL
Congenital Malformation Registry of Northern Lombardy

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

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

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

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

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

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

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Roberto Tessandori, Lucia Preto, Anna Maghini, Maria Eugenia Sanoja, Daniele Vergani, Andrea Tittarelli, Sabrina Fabiano

Congenital Malformation Registry of Northern Lombardy (CMRL)
National Cancer Institute
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ITALY-Lombardy: CMRL, 2009*

Live births (LB)	10,069
Stillbirths (SB)	41
Total births	10,110
Number of terminations of pregnancy (ToP) for birth defects	33

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	1	1.98
Spina bifida	1	0	1	1.98
Encephalocele	0	1	0	0.99
Microcephaly	3	0	0	2.97
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	2	1	5	7.91
Anophthalmos	1	0	0	0.99
Microphthalmos	1	0	0	0.99
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.99
Microtia	1	0	0	0.99
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	3	0	1	3.96
Tetralogy of Fallot	3	0	0	2.97
Hypoplastic left heart syndrome	2	0	0	1.98
Coarctation of aorta	6	0	0	5.93
Choanal atresia, bilateral	1	0	0	0.99
Cleft palate without cleft lip	4	0	0	3.96
Cleft lip with or without cleft palate	9	0	1	9.89
Oesophageal atresia/stenosis with or without fistula	2	0	0	1.98
Small intestine atresia/stenosis	3	0	0	2.97
Anorectal atresia/stenosis	3	0	0	2.97
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	23	0	0	22.75
Epispadias	0	0	0	0.00
Indeterminate sex	3	0	0	2.97
Renal agenesis	6	0	2	7.91
Cystic kidney	1	0	0	0.99
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	2	0	0	1.98
Total Limb reduction defects (include unspecified)	5	0	1	5.93
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	0	0	0	0.00
Omphalocele	0	0	1	0.99
Gastroschisis	1	0	1	1.98
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	0	0	1	0.99
Trisomy 18	0	0	2	1.98
Down syndrome, all ages (include age unknown)	14	0	7	20.77
<20	0	0	0	0.00
20-24	0	0	0	0.00
25-29	2	0	0	9.10
30-34	4	0	1	13.19
35-39	5	0	2	27.48
40-44	3	0	4	129.39
45+	0	0	0	0.00
unknown	0	0	0	---

nr = not reported
(*) Data for the provinces of Sondrio and Varese

Italy: North East

North East Italy Registry of Congenital Malformations

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

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

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

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

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

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

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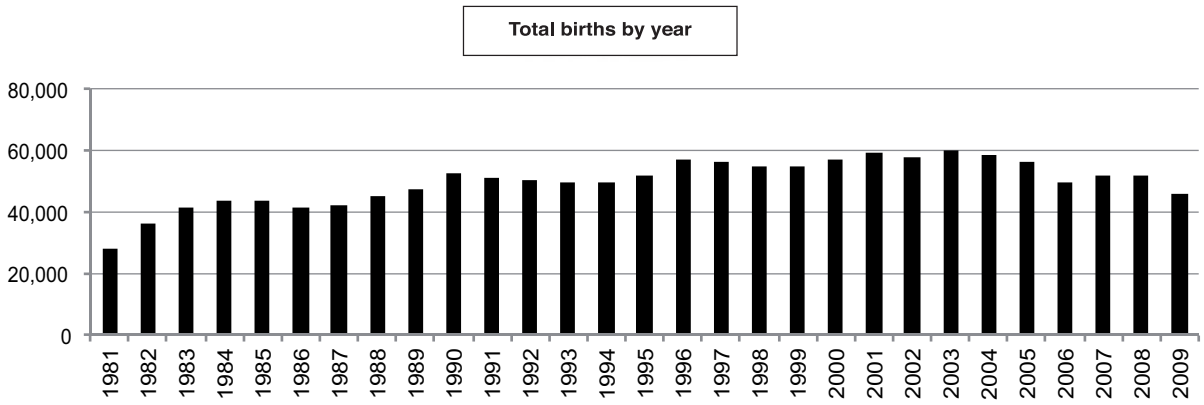
Italy: North East



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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	16	72.7	Cystic kidney	3	5.7
Spina bifida	21	61.8	Limb reduction defects	11	23.4
Encephalocele	6	66.7	Diaphragmatic hernia	5	16.7
Holoprosencephaly	1	33.3	Omphalocele	7	33.3
Hydrocephaly	30	36.6	Gastroschisis	4	25.0
Hypoplastic left heart syndrome	6	31.6	Trisomy 13	5	100.0
Cleft palate without cleft lip	6	5.8	Trisomy 18	10	90.9
Cleft lip with or without cleft palate	8	5.8	Down syndrome	105	33.9
Renal agenesis	15	23.8			

Total ToPs with births defects = 250 (Ratio ToPs/Births: 1.68 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: North East, 2009

Live births (LB)	45,523
Stillbirths (SB)	44
Total births	45,567
Number of terminations of pregnancy (ToP) for birth defects	107

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	3	0.66
Spina bifida	0	0	5	1.10
Encephalocele	0	0	2	0.44
Microcephaly	4	1	0	1.10
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	1	0	9	2.19
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.22
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	0	0	0	0.00
Microtia	2	0	1	0.66
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	4	0	0	0.88
Tetralogy of Fallot	3	0	0	0.66
Hypoplastic left heart syndrome	1	0	4	1.10
Coarctation of aorta	5	0	0	1.10
Choanal atresia, bilateral	4	0	0	0.88
Cleft palate without cleft lip	19	0	1	4.39
Cleft lip with or without cleft palate	27	0	2	6.36
Oesophageal atresia/stenosis with or without fistula	7	0	0	1.54
Small intestine atresia/stenosis	5	0	0	1.10
Anorectal atresia/stenosis	11	0	2	2.85
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	15	0	0	3.29
Epispadias	0	0	0	0.00
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	5	0	4	1.98
Cystic kidney	7	0	1	1.76
Bladder exstrophy	2	0	0	0.44
Polydactyly, preaxial	40	0	2	9.22
Total Limb reduction defects (include unspecified)	6	0	1	1.54
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	1.54
Omphalocele	5	0	1	1.32
Gastroschisis	6	0	3	1.98
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	0	0.00
Trisomy 18	0	0	1	0.22
Down syndrome, all ages (include age unknown)	65	0	33	21.51
<20	0	0	0	nr
20-24	1	0	2	nr
25-29	3	0	2	nr
30-34	5	0	9	nr
35-39	7	0	10	nr
40-44	6	0	8	nr
45+	0	0	0	nr
unknown	43	0	2	---

nr = not reported

Italy: North East, Previous years rates 1981 - 2009

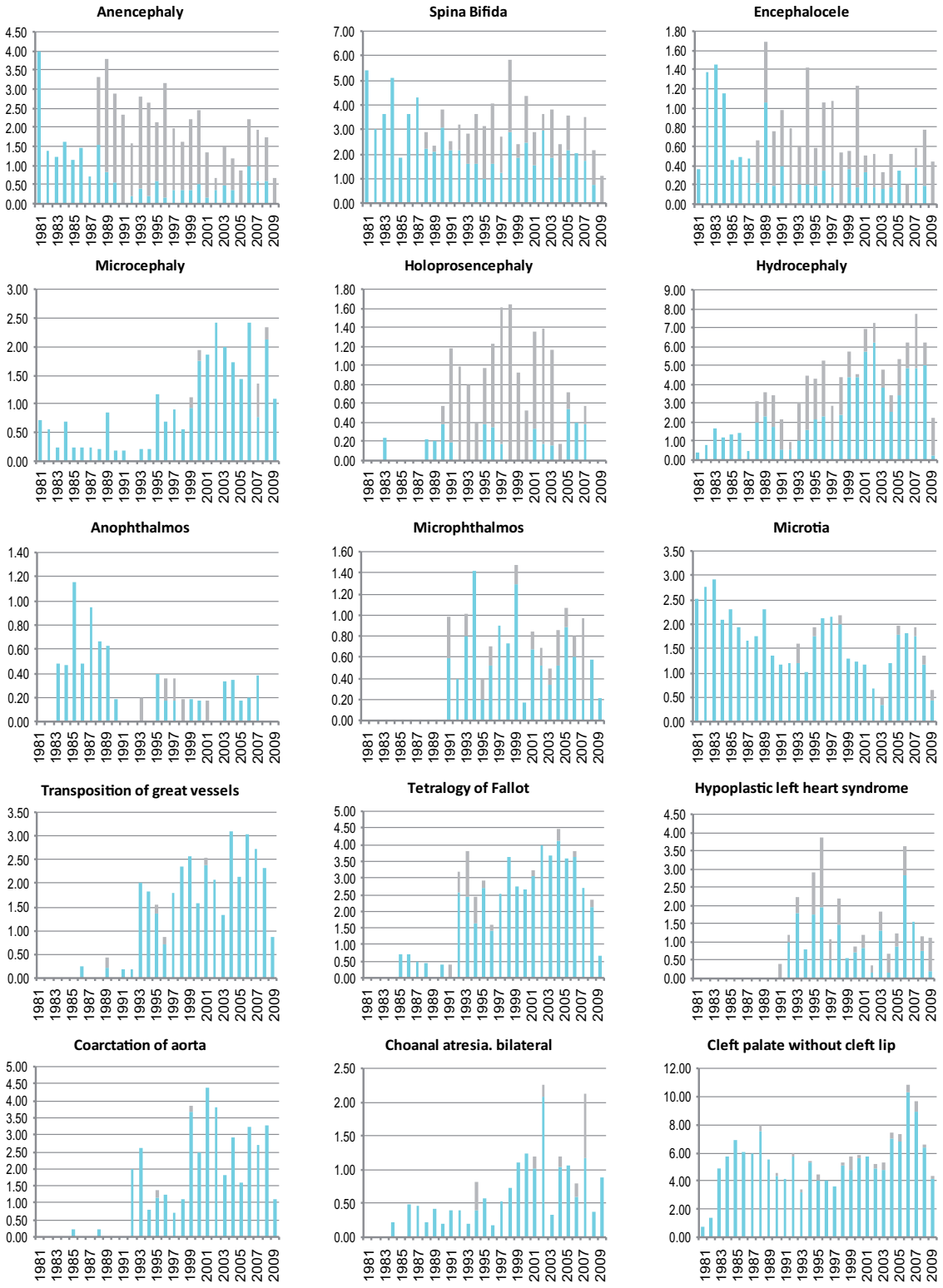
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984*	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**148,426**	**219,536**	**252,816**	**273,566**	**292,184**	**254,501**	
Anencephaly	1.89	2.14	2.45	2.23	1.44	1.49	
Spina bifida	4.24	2.96	3.20	3.62	3.42	2.51	
Encephalocele	1.15	0.77	0.91	0.77	0.62	0.47	
Microcephaly	0.54	0.36	0.16	0.88	1.99	1.73	
Holoprosencephaly	0.07	0.09	0.79	1.28	0.92	0.35	
Hydrocephaly	1.08	2.05	2.81	4.50	5.41	5.62	
Anophthalmos	0.27	0.77	0.08	0.29	0.21	0.16	
Microphthalmos	0.00	0.00	0.75	0.84	0.62	0.75	
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	nr	nr	
Anotia	0.20	0.18	0.28	0.18	0.21	0.24	
Microtia	2.56	2.00	1.27	1.94	0.96	1.57	
Unspecified Anotia/Microtia	0.00	0.05	0.12	0.22	0.17	0.40*	
Transposition of great vessels	0.00	0.14	0.83	1.83	2.12	2.24	
Tetralogy of Fallot	0.00	0.46	2.02	2.67	3.59	2.67	
Hypoplastic left heart syndrome	0.00	0.00	0.91	2.12	0.99	1.73	
Coarctation of aorta	0.00	0.09	1.07	1.64	3.08	2.40	
Choanal atresia, bilateral	0.07	0.32	0.40	0.62	1.23	1.06	
Cleft palate without cleft lip	3.50	6.47	4.71	4.61	5.89	7.82	
Cleft lip with or without cleft palate	8.83	8.79	7.55	8.22	7.77	9.31	
Oesophageal atresia/stenosis with or without fistula	2.29	2.23	2.81	2.49	3.25	2.44	
Small intestine atresia/stenosis	0.40	0.64	1.19	0.84	2.57	2.59	
Anorectal atresia/stenosis	2.49	3.33	2.41	2.67	2.70	4.20	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	
Hypospadias	6.87	6.70	6.13	9.18	22.55	15.95	
Epispadias	0.07	0.14	0.12	0.22	0.27	0.16	
Indeterminate sex	nr	nr	nr	nr	nr	nr	
Renal agenesis	0.74	0.68	0.67	0.69	0.34	3.03	
Cystic kidney	0.00	0.00	0.16	0.73	1.44	2.32	
Bladder exstrophy	0.34	0.14	0.44	0.22	0.24	0.35	
Polydactyly, preaxial	1.62	2.32	2.49	2.01	1.68	4.87	
Total Limb reduction defects (include unspecified)	5.79	5.97	5.97	5.08	4.11	3.81	
Transverse	3.44	3.37	2.85	2.85	1.64	1.43*	
Preaxial	0.00	0.09	0.79	0.69	0.34	0.53*	
Postaxial	0.00	0.14	0.16	0.15	0.31	0.18*	
Intercalary	0.54	0.87	0.95	0.37	0.31	0.36*	
Mixed	1.82	1.14	0.16	0.22	0.10	0.00*	
Unspecified	0.00	0.32	1.07	0.84	1.33	3.57*	
Diaphragmatic hernia	0.34	0.64	0.63	0.84	1.85	1.85	
Omphalocele	1.21	1.46	1.38	1.24	1.40	1.18	
Gastroschisis	0.67	0.87	0.71	0.48	0.79	1.06	
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	nr	
Prune belly sequence	0.07	0.00	0.32	0.22	0.00	0.00	
Trisomy 13	0.81	0.64	0.83	0.99	1.27	0.63	
Trisomy 18	0.94	1.59	2.22	2.63	2.43	0.98	
Down syndrome, all ages (include age unknown)	13.88	15.76	16.02	16.74	17.76	19.06	
<20	nr	nr	nr	nr	nr	nr	
20-24	nr	nr	nr	nr	nr	nr	
25-29	nr	nr	nr	nr	nr	nr	
30-34	nr	nr	nr	nr	nr	nr	
35-39	nr	nr	nr	nr	nr	nr	
40-44	nr	nr	nr	nr	nr	nr	
45+	nr	nr	nr	nr	nr	nr	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

Italy: North East

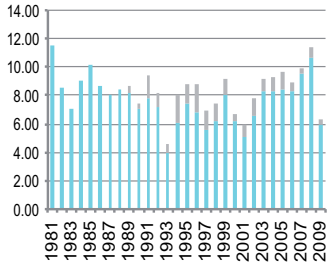
Time trends 1981-2009 (Birth prevalence rates per 10,000)



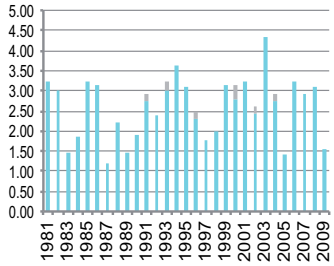
Note: L+S rates, ToP rates

Italy: North East

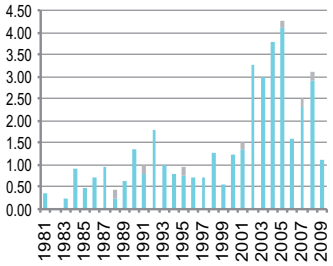
Cleft lip with or without cleft palate



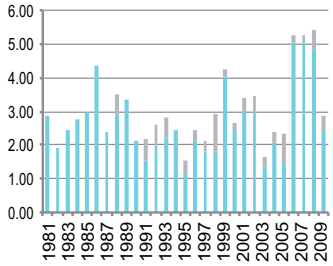
Oesophageal atresia/stenosis with or without fistula



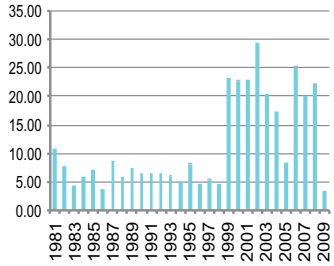
Small intestine atresia/stenosis



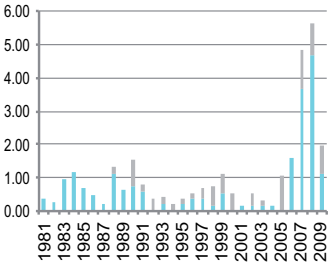
Anorectal atresia/stenosis



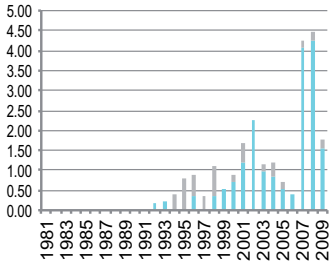
Hypospadias



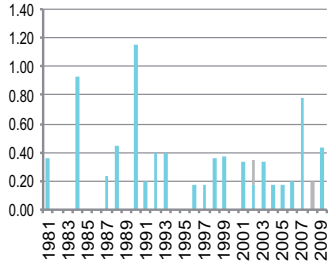
Renal agenesis



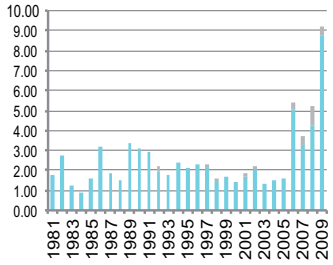
Cystic kidney



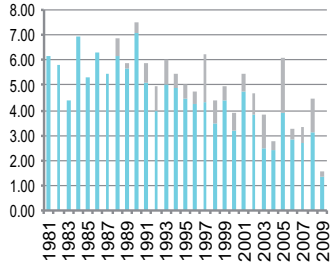
Bladder exstrophy



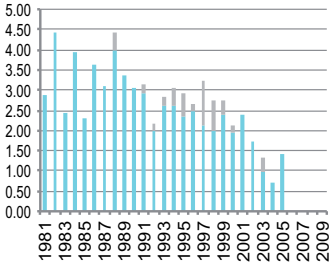
Polydactyly, preaxial



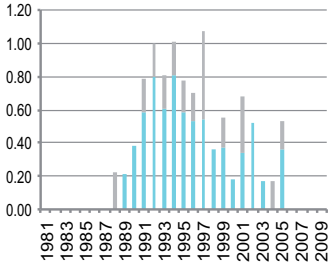
Limb reduction defects



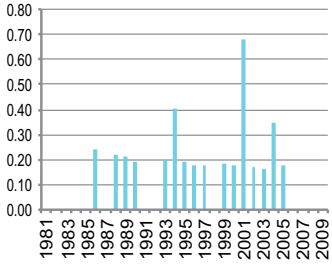
Limb reduction defects - transverse



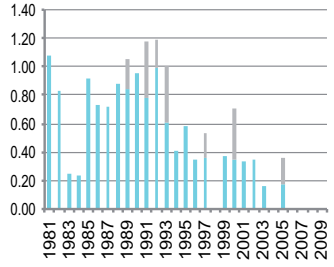
Limb reduction defects - preaxial



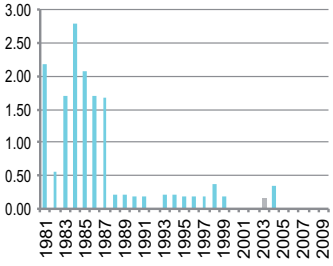
Limb reduction defects - postaxial



Limb reduction defects - intercalary

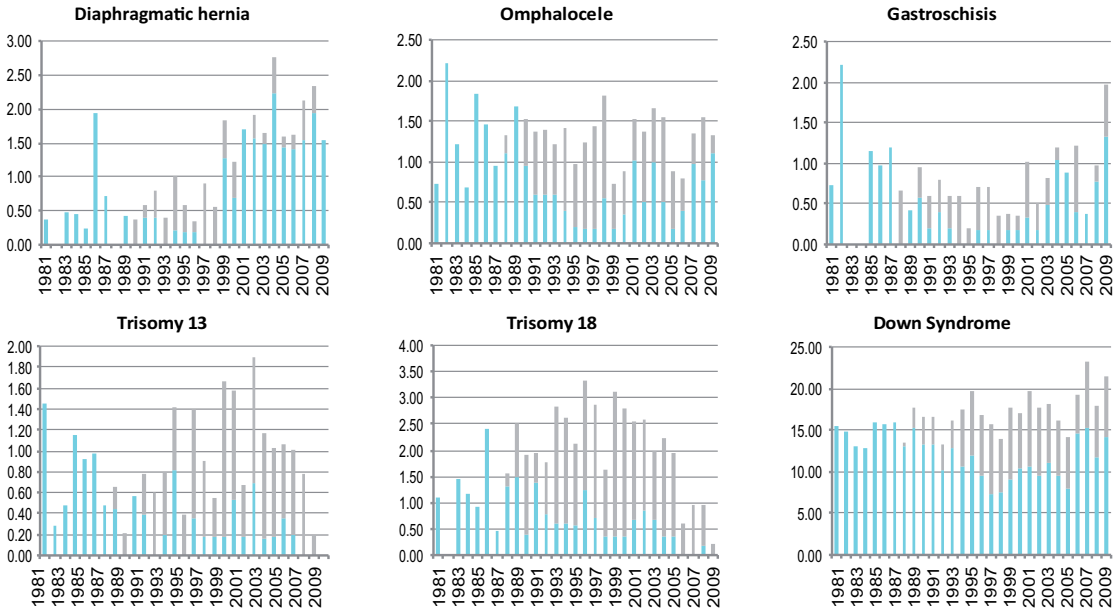


Limb reduction defects - mixed



Note: L+S rates, ToP rates

Italy: North East



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 millions inhabitants and 25,000 births/year). Stillbirths of 20 weeks or more gestation and induced abortions after prenatal diagnosis of birth defects are systematically included. Malformed babies diagnosed within the first year of life are also registered.

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

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

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

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

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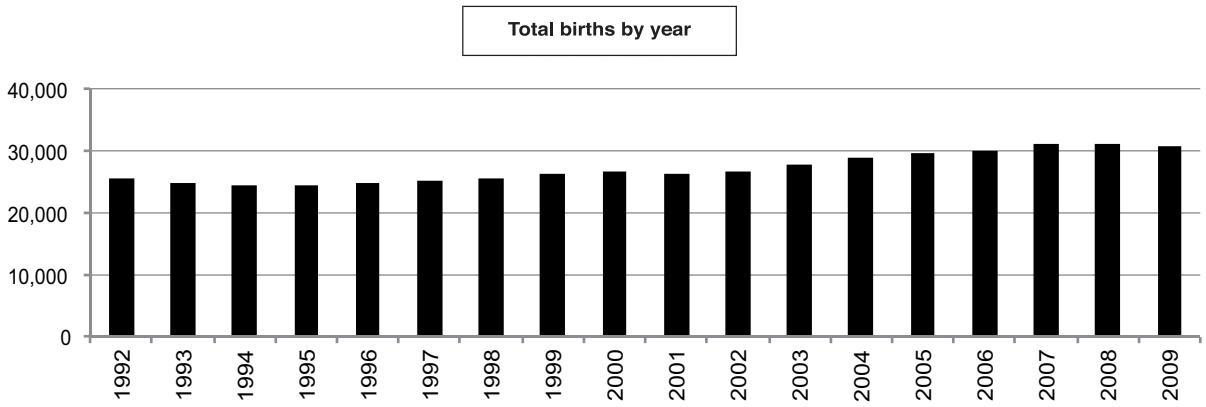
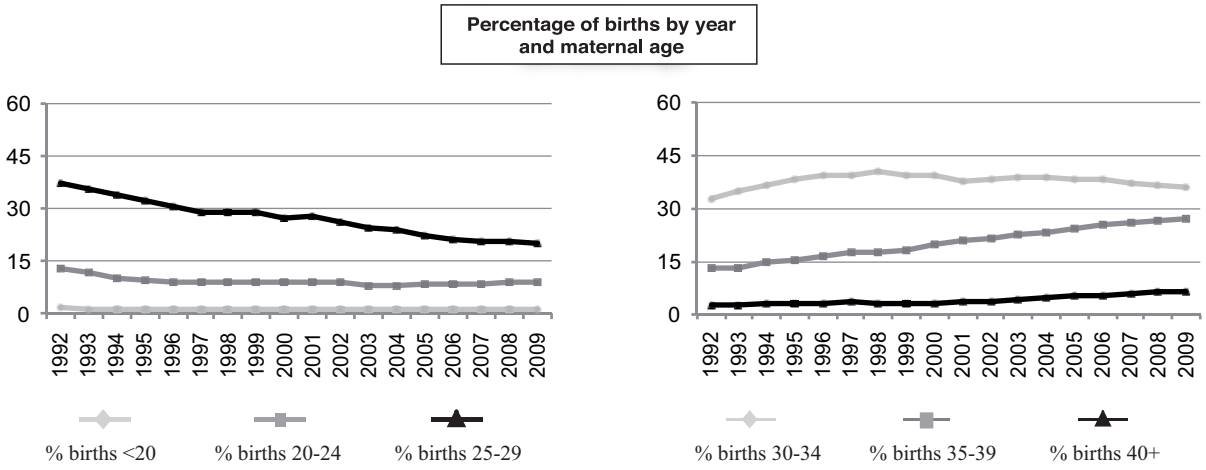
E-mail: apier@ifc.cnr.it

Website: www.rtdc.it

Italy - Tuscany: RTDC





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	14	100.0	Cystic kidney	10	25.6
Spina bifida	26	83.9	Limb reduction defects	13	31.0
Encephalocele	5	55.6	Diaphragmatic hernia	2	11.8
Holoprosencephaly	9	75.0	Omphalocele	21	87.5
Hydrocephaly	19	70.4	Gastroschisis	4	50.0
Hypoplastic left heart syndrome	13	61.9	Trisomy 13	15	93.8
Cleft palate without cleft lip	3	8.3	Trisomy 18	36	87.8
Cleft lip with or without cleft palate	16	27.6	Down syndrome	124	69.7
Renal agenesis	6	75.0			

Total ToPs with births defects = 417 (Ratio ToPs/Births: 4.50 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy - Tuscany: RTDC, 2009

Live births (LB)	30,488
Stillbirths (SB)	81
Total births	30,569
Number of terminations of pregnancy (ToP) for birth defects	153

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	6	1.96
Spina bifida	0	1	7	2.62
Encephalocele	1	1	0	0.65
Microcephaly	3	0	0	0.98
Holoprosencephaly	2	0	1	0.98
Hydrocephaly	5	1	4	3.27
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	1	0.65
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.65
Microtia	1	0	1	0.65
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	10	0	0	3.27
Tetralogy of Fallot	2	0	1	0.98
Hypoplastic left heart syndrome	1	0	8	2.94
Coarctation of aorta	7	0	0	2.29
Choanal atresia, bilateral	5	0	0	1.64
Cleft palate without cleft lip	13	0	0	4.25
Cleft lip with or without cleft palate	21	0	7	9.16
Oesophageal atresia/stenosis with or without fistula	10	0	1	3.60
Small intestine atresia/stenosis	3	0	0	0.98
Anorectal atresia/stenosis	9	0	1	3.27
Undescended testis (36 weeks of gestation or later)	28	0	0	9.16
Hypospadias	50	0	0	16.36
Epispadias	1	0	0	0.33
Indeterminate sex	1	0	1	0.65
Renal agenesis	0	0	0	0.00
Cystic kidney	13	1	2	5.23
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	3	0	0	0.98
Total Limb reduction defects (include unspecified)	12	0	5	5.56
Transverse	11	0	3	4.58
Preaxial	1	0	2	0.98
Postaxial	2	0	1	0.98
Intercalary	0	0	1	0.33
Mixed	0	0	0	0.00
Unspecified	1	0	0	0.33
Diaphragmatic hernia	7	0	0	2.29
Omphalocele	0	0	8	2.62
Gastroschisis	0	0	1	0.33
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	6	1.96
Trisomy 18	1	0	12	4.25
Down syndrome, all ages (include age unknown)	19	0	57	24.86
<20	1	0	0	26.46
20-24	0	0	2	7.36
25-29	2	0	1	4.91
30-34	2	0	10	10.95
35-39	6	0	23	34.71
40-44	5	0	19	123.20
45+	1	0	2	337.08
unknown	2	0	0	---

Italy - Tuscany: RTDC, Previous years rates 1992 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994*	1995-1999	2000-2004	2005-2009
Total births				**74,844**	**125,638**	**136,262**	**152,159**
Anencephaly				2.67	2.39	1.32	2.04
Spina bifida				2.67	3.02	3.30	2.56
Encephalocele				1.07	0.96	0.29	0.85
Microcephaly				1.47	0.88	0.81	0.66
Holoprosencephaly				0.67	0.72	1.10	1.05
Hydrocephaly				3.07	2.79	3.89	3.22
Anophthalmos				0.00	0.08	0.22	0.13
Microphthalmos				0.67	0.24	0.81	0.59
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.07	0.00
Anotia				0.40	0.32	0.37	0.33
Microtia				0.40	0.72	0.29	0.53
Unspecified Anotia/Microtia				0.00	0.00	0.00	0.00
Transposition of great vessels				2.41	1.59	3.52	2.83
Tetralogy of Fallot				1.87	2.79	2.50	2.56
Hypoplastic left heart syndrome				2.27	1.35	2.72	2.17
Coarctation of aorta				2.41	2.79	2.28	2.30
Choanal atresia, bilateral				0.13	0.08	0.59	0.59
Cleft palate without cleft lip				4.01	3.66	4.26	3.42
Cleft lip with or without cleft palate				8.42	5.49	6.60	5.85
Oesophageal atresia/stenosis with or without fistula				2.14	2.55	2.35	2.30
Small intestine atresia/stenosis				1.07	0.64	1.17	1.05
Anorectal atresia/stenosis				1.60	1.99	3.16	1.77
Undescended testis (36 weeks of gestation or later)				3.47	6.53	10.20	5.45
Hypospadias				5.75	3.18	6.75	10.52
Epispadias				0.27	0.24	0.22	0.26
Indeterminate sex				0.94	0.64	0.51	0.59
Renal agenesis				1.87	1.43	0.88	0.72
Cystic kidney				3.34	3.26	4.40	4.21
Bladder exstrophy				0.40	0.16	0.22	0.26
Polydactyly, preaxial				0.80	0.96	1.39	0.99
Total Limb reduction defects (include unspecified)				5.08	4.78	6.53	4.47
Transverse				4.01	2.79	4.40	2.50
Preaxial				0.13	0.32	0.66	0.53
Postaxial				0.13	0.32	0.15	0.46
Intercalary				0.27	0.56	0.59	0.20
Mixed				0.27	0.48	0.29	0.07
Unspecified				0.00	0.00	0.66	1.31
Diaphragmatic hernia				1.20	1.43	2.57	1.51
Omphalocele				2.27	1.27	1.83	2.10
Gastroschisis				0.53	0.40	0.59	0.85
Unspecified Omphalocele/Gastroschisis				0.40	0.32	0.22	0.13
Prune belly sequence				0.13	0.16	0.00	0.13
Trisomy 13				0.40	0.80	1.32	1.64
Trisomy 18				2.81	3.34	2.79	3.55
Down syndrome, all ages (include age unknown)				13.49	16.79	16.59	17.61
<20				0.00	0.00	0.00	5.19
20-24				3.49	8.04	4.34	6.13
25-29				8.35	8.71	3.17	4.71
30-34				10.11	13.65	9.25	6.53
35-39				31.57	28.31	26.98	26.82
40-44				66.19	104.63	156.77	92.78
45+				236.22	45.45	157.89	163.93
unknown				---	---	---	---

* data include less than 5 years

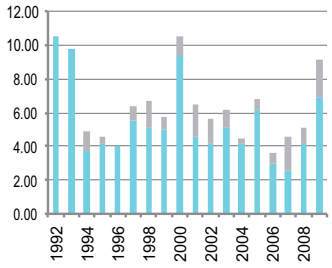
Italy - Tuscany: RTDC

Time trends 1992-2009 (Birth prevalence rates per 10,000)

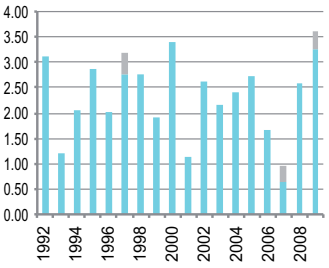
Note: L+S rates, ToP rates

Italy - Tuscany: RTDC

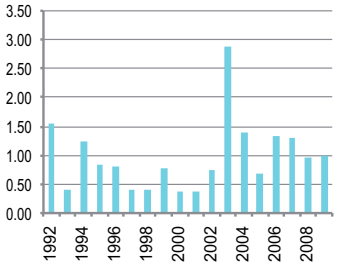
Cleft lip with or without cleft palate



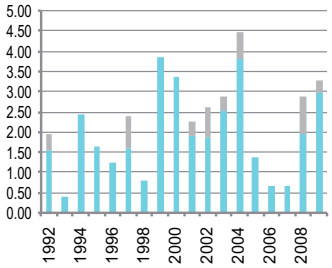
Oesophageal atresia/stenosis with or without fistula



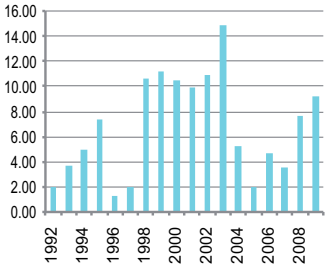
Small intestine atresia/stenosis



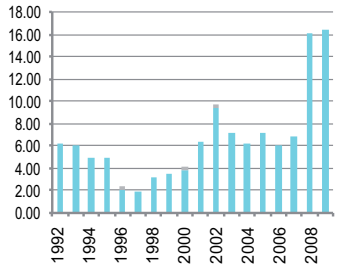
Anorectal atresia/stenosis



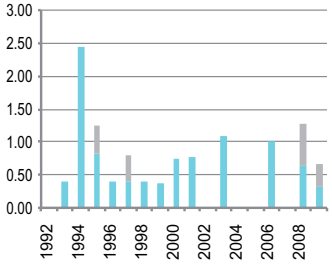
Undescended testis



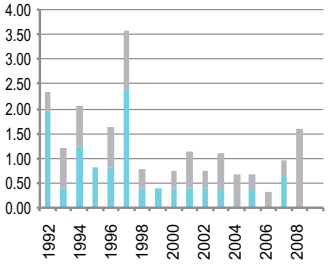
Hypospadias



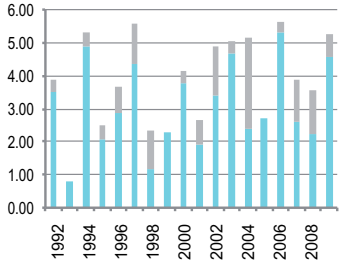
Indeterminate sex



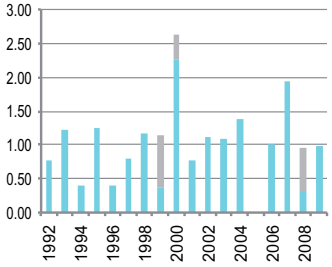
Renal agenesis



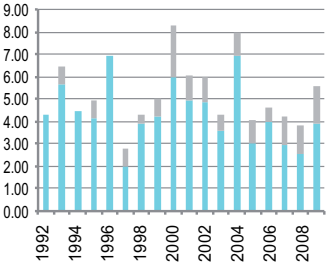
Cystic kidney



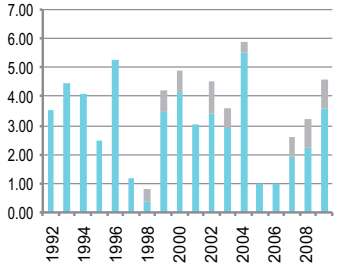
Polydactyly. preaxial



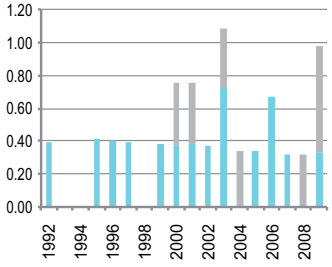
Limb reduction defects



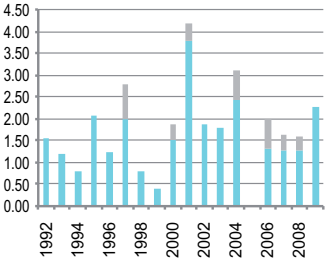
Limb reduction defects - transverse



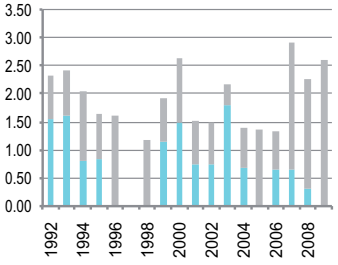
Limb reduction defects - preaxial



Diaphragmatic hernia

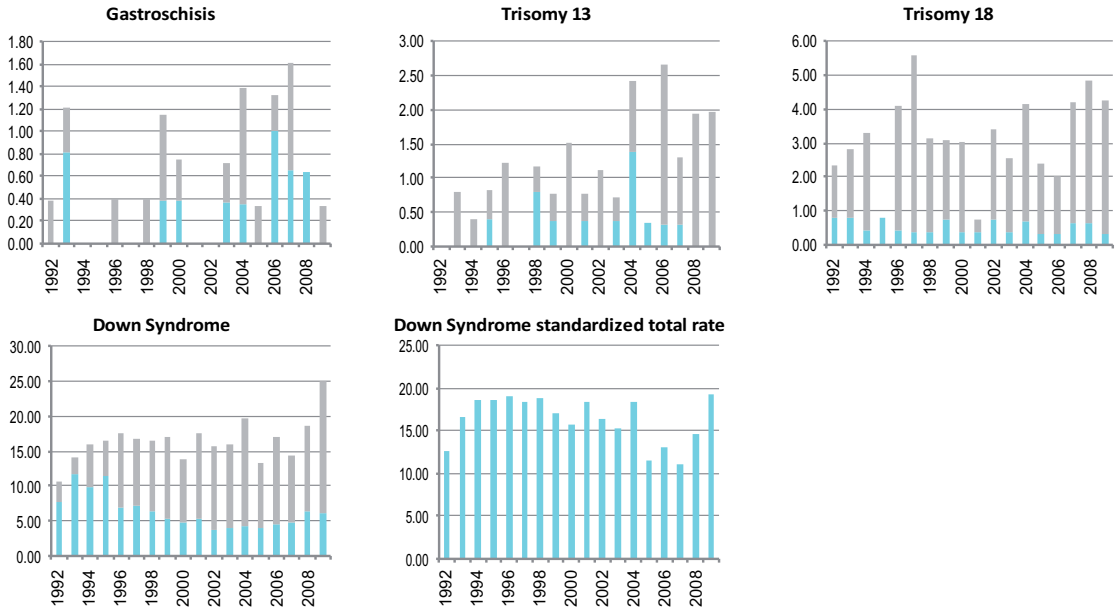


Omphalocele



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.

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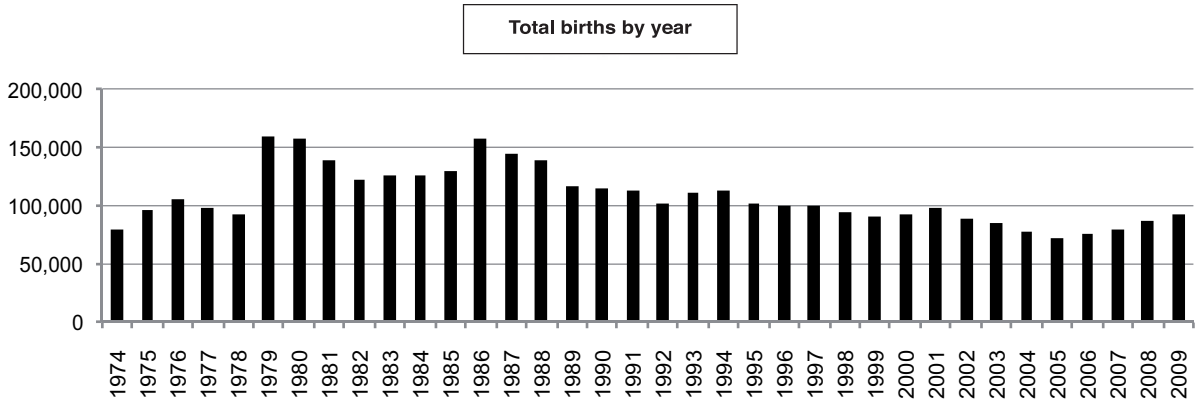
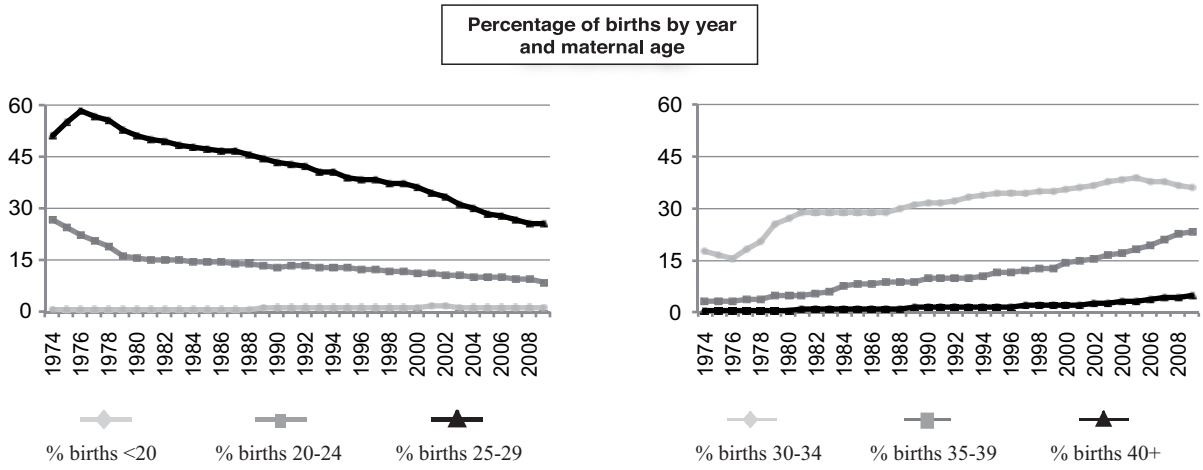
Japan: JAOG


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


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
% births <20
% births 20-24
% births 25-29
60
45
30
15
0
1974 1976 1978 1980 1982 1984 1986 1988 1990 1992 1994 1996 1998 2000 2002 2004 2006 2008
% births 30-34
% births 35-39
% births 40+

Japan JAOG, 2009

Live births (LB)	91,674
Stillbirths (SB)	582
Total births	92,256
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	2	nr	0.54
Spina bifida	55	2	nr	6.18
Encephalocele	7	1	nr	0.87
Microcephaly	8	5	nr	1.41
Holoprosencephaly	6	3	nr	0.98
Hydrocephaly	65	3	nr	7.37
Anophthalmos	2	0	nr	0.22
Microphthalmos	5	1	nr	0.65
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	0	0	nr	0.00
Microtia	19	3	nr	2.38
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	43	0	nr	4.66
Tetralogy of Fallot	59	5	nr	6.94
Hypoplastic left heart syndrome	30	6	nr	3.90
Coarctation of aorta	63	2	nr	7.05
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	36	0	nr	3.90
Cleft lip with or without cleft palate	168	15	nr	19.84
Oesophageal atresia/stenosis with or without fistula	35	4	nr	4.23
Small intestine atresia/stenosis	78	6	nr	9.11
Anorectal atresia/stenosis	67	5	nr	7.80
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	50	0	nr	5.42
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	19	4	nr	2.49
Cystic kidney	28	2	nr	3.25
Bladder exstrophy	2	1	nr	0.33
Polydactyly, preaxial	65	1	nr	7.15
Total Limb reduction defects (include unspecified)	43	3	nr	4.99
Transverse	3	1	nr	0.43
Preaxial	13	0	nr	1.41
Postaxial	2	0	nr	0.22
Intercalary	12	0	nr	1.30
Mixed	12	2	nr	1.52
Unspecified	1	0	nr	0.11
Diaphragmatic hernia	53	8	nr	6.61
Omphalocele	25	7	nr	3.47
Gastroschisis	23	0	nr	2.49
Unspecified Omphalocele/Gastroschisis	1	1	nr	0.22
Prune belly sequence	2	0	nr	0.22
Trisomy 13	9	5	nr	1.52
Trisomy 18	56	29	nr	9.21
Down syndrome, all ages (include age unknown)	98	3	nr	10.95
<20	0	0	nr	0.00
20-24	3	0	nr	3.73
25-29	10	1	nr	4.66
30-34	18	0	nr	5.39
35-39	45	1	nr	21.31
40+	20	1	nr	46.77
unknown	0	0	nr	---

nr = not reported

Japan: JAOG, Previous years rates 1974 - 2009

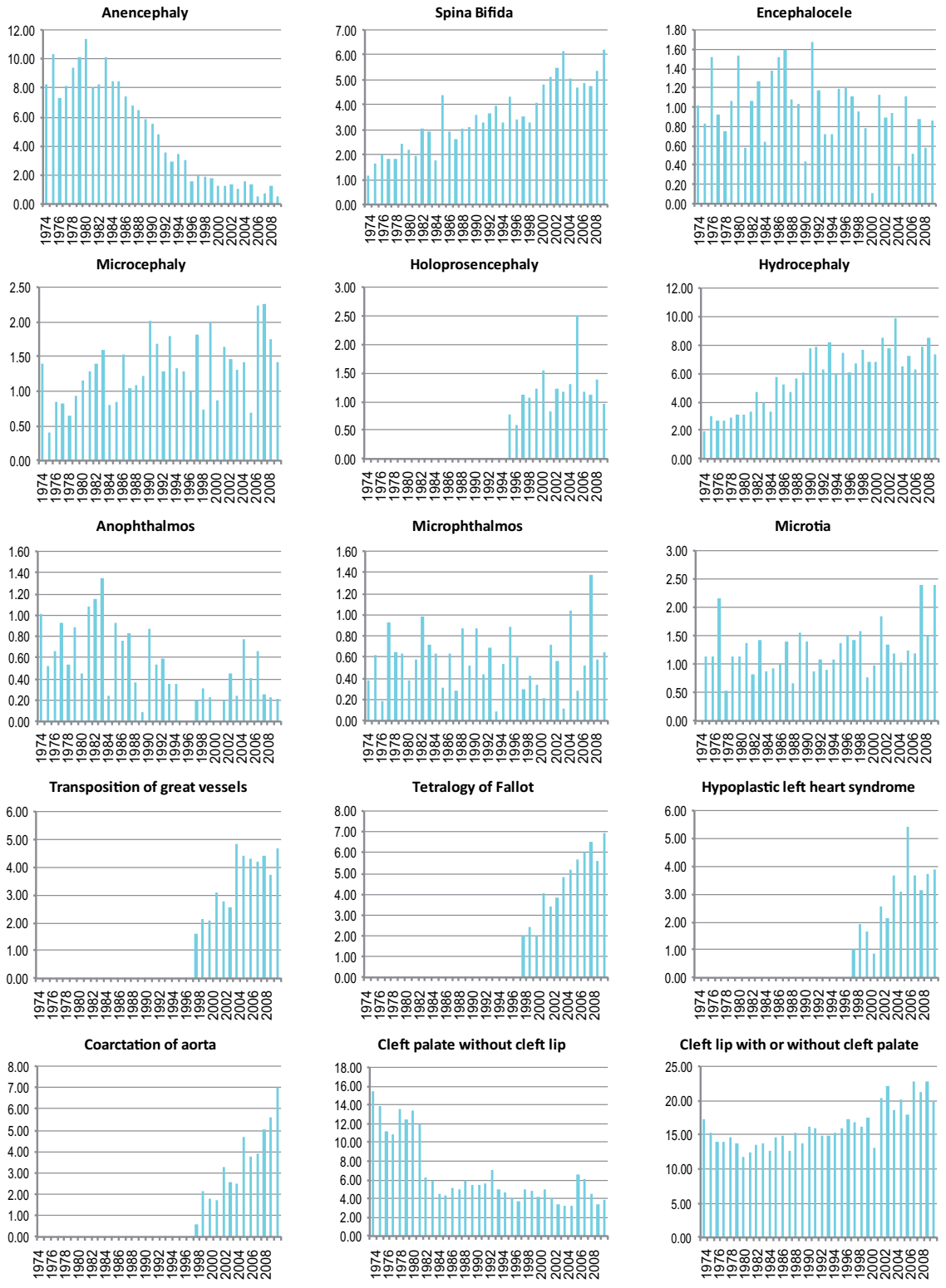
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**630,508**	**668,362**	**685,695**	**551,995**	**484,401**	**439,875**	**406,250**
Anencephaly	9.01	9.32	7.03	4.06	2.09	1.27	0.89
Spina bifida	1.90	2.35	3.19	3.55	3.74	5.32	5.22
Encephalocele	1.03	1.03	1.34	0.94	1.05	0.70	0.79
Microcephaly	0.84	1.24	1.15	1.63	1.36	1.34	1.67
Holoprosencephaly	nr	nr	nr	nr	0.95	1.20	1.40
Hydrocephaly	2.78	3.65	5.44	7.25	6.92	7.91	7.48
Anophthalmos	0.76	0.84	0.61	0.54	0.14	0.32	0.34
Microphthalmos	0.57	0.64	0.53	0.53	0.52	0.52	0.69
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	nr	nr	0.00
Microtia	1.06	1.14	1.09	1.07	1.34	1.30	1.77
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	0.00
Transposition of great vessels	nr	nr	nr	nr	1.94*	3.48	4.26
Tetralogy of Fallot	nr	nr	nr	nr	2.15*	4.21	6.18
Hypoplastic left heart syndrome	nr	nr	nr	nr	1.52*	2.43	3.94
Coarctation of aorta	nr	nr	nr	nr	1.48*	2.91	5.17
Choanal atresia, bilateral	nr	nr	nr	nr	nr	nr	0.00
Cleft palate without cleft lip	12.74	8.71	5.18	5.53	4.38	3.82	4.82
Cleft lip with or without cleft palate	14.62	12.79	14.25	15.47	16.78	18.89	20.97
Oesophageal atresia/stenosis with or without fistula	1.19*	1.03	1.60	2.25	2.81	4.39	4.60
Small intestine atresia/stenosis	nr	nr	nr	nr	4.44*	5.66	7.68
Anorectal atresia/stenosis	4.04	3.55	4.24	4.17	4.38	5.46	6.70
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	1.74	2.21	2.36	3.10	2.93	4.18	4.36
Epispadias	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr	nr	nr	nr
Renal agenesis	nr	nr	0.95*	1.58	1.49	2.14	2.39
Cystic kidney	nr	nr	nr	nr	2.79*	4.30	3.94
Bladder exstrophy	0.17*	0.13	0.16	0.13	0.17	0.30	0.22
Polydactyly, preaxial	nr	nr	5.28*	6.54	6.19	6.48	6.62
Total Limb reduction defects (include unspecified)	nr	nr	nr	3.23*	3.32	3.43	3.79
Transverse	nr	nr	nr	0.36*	0.37	0.32	0.30
Preaxial	nr	nr	nr	0.58*	0.50	0.66	0.84
Postaxial	nr	nr	nr	0.17*	0.33	0.27	0.49
Intercalary	nr	nr	nr	1.39*	1.09	0.86	0.81
Mixed	nr	nr	nr	0.40*	0.64	0.82	1.03
Unspecified	nr	nr	nr	0.31*	0.39	0.50	0.32
Diaphragmatic hernia	nr	nr	2.25*	2.92	3.67	6.16	5.81
Omphalocele	0.97	1.38	2.63	3.32	3.24	3.52	3.94
Gastroschisis	1.08	0.84	1.18	1.59	1.88	2.55	2.56
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.03	0.42	0.19	0.34	0.20
Prune belly sequence	nr	nr	nr	nr	0.04	0.02	0.10
Trisomy 13	nr	nr	nr	0.36*	0.78	1.34	2.04
Trisomy 18	nr	nr	nr	2.33*	3.34	7.66	8.66
Down syndrome, all ages (include age unknown)	3.37*	4.94	5.94	6.05	8.26	9.64	11.57
<20	nr	nr	nr	8.33*	0.00	7.32	1.90
20-24	nr	nr	nr	2.07*	3.18	3.17	4.14
25-29	nr	nr	nr	4.08*	5.24	4.93	5.60
30-34	nr	nr	nr	4.96*	8.38	8.07	8.63
35-39	nr	nr	nr	16.65*	17.37	20.57	21.78
40-44	nr	nr	nr	67.33*	50.31	57.46	42.52
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years or 6 years

Japan: JAOG

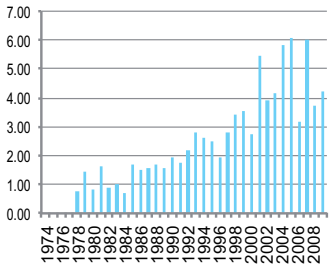
Time trends 1974-2009 (Birth prevalence rates per 10,000)



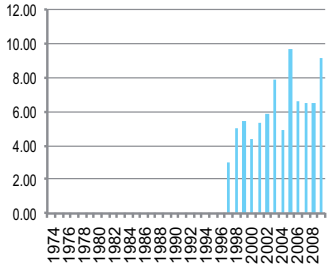
Note: L+S rates

Japan: JAOG

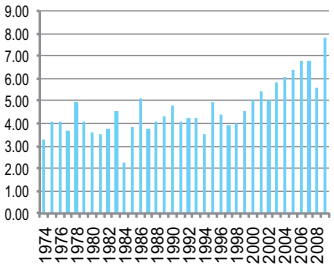
Oesophageal atresia/stenosis with or without fistula



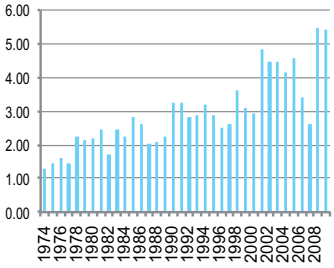
Small intestine atresia/stenosis



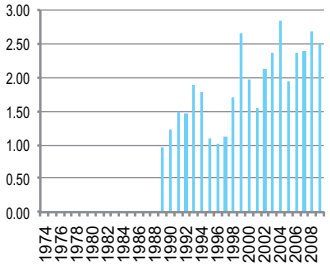
Anorectal atresia/stenosis



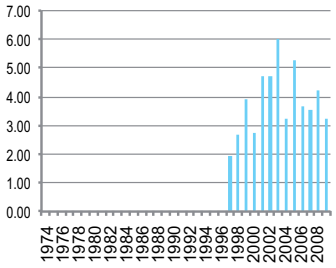
Hypospadias



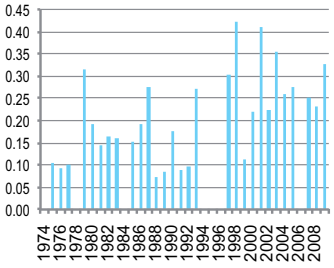
Renal agenesis



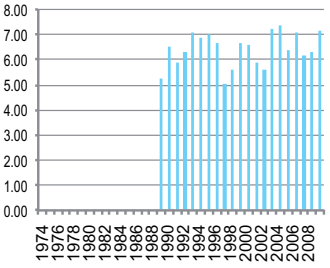
Cystic kidney



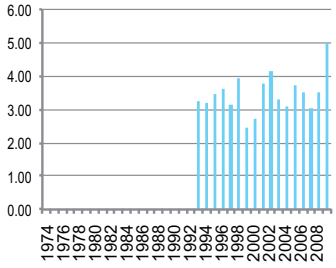
Bladder exstrophy



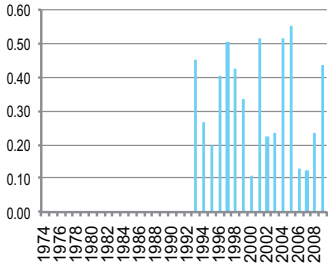
Polydactyly, preaxial



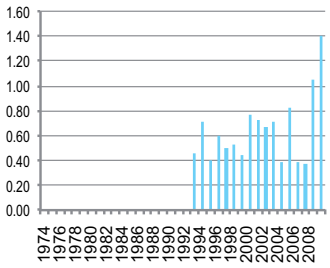
Limb reduction defects



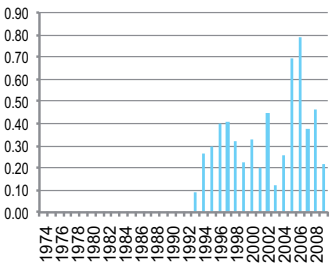
Limb reduction defects - transverse



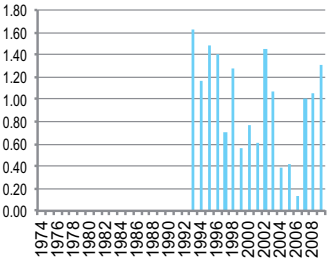
Limb reduction defects - preaxial



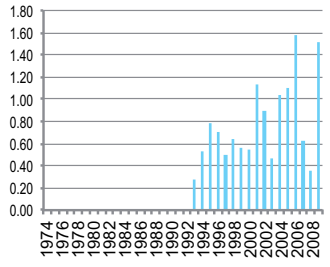
Limb reduction defects - postaxial



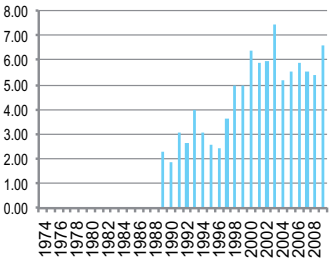
Limb reduction defects - intercalary



Limb reduction defects - mixed

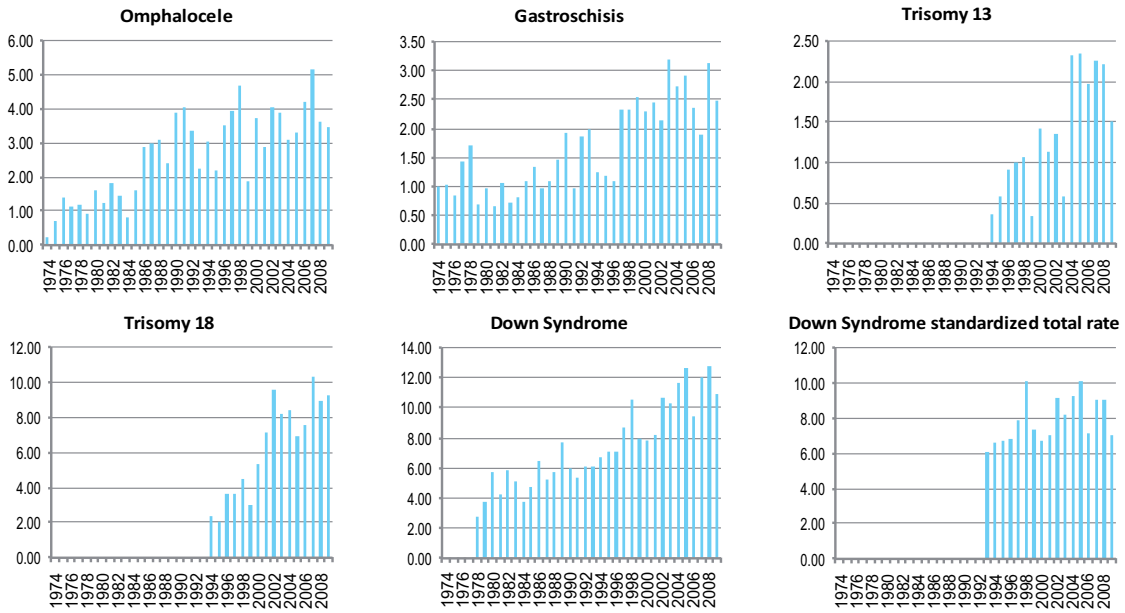


Diaphragmatic hernia



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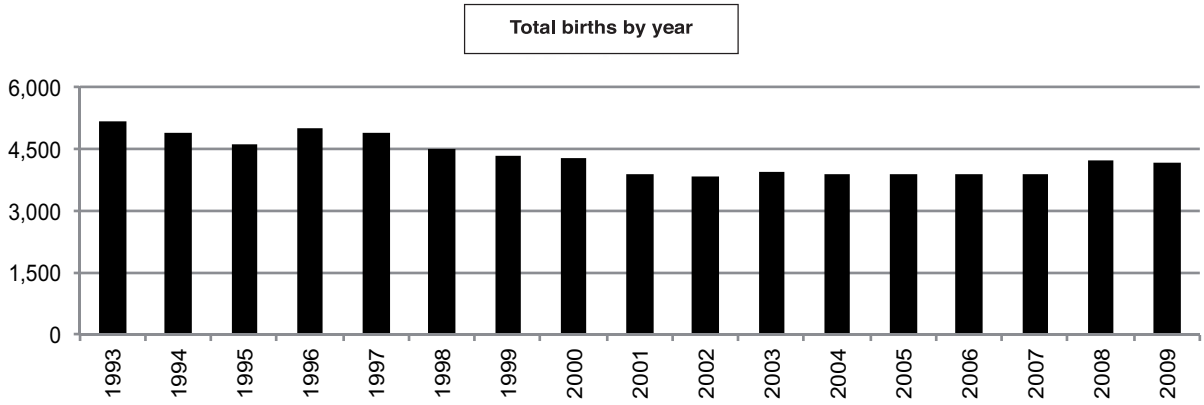
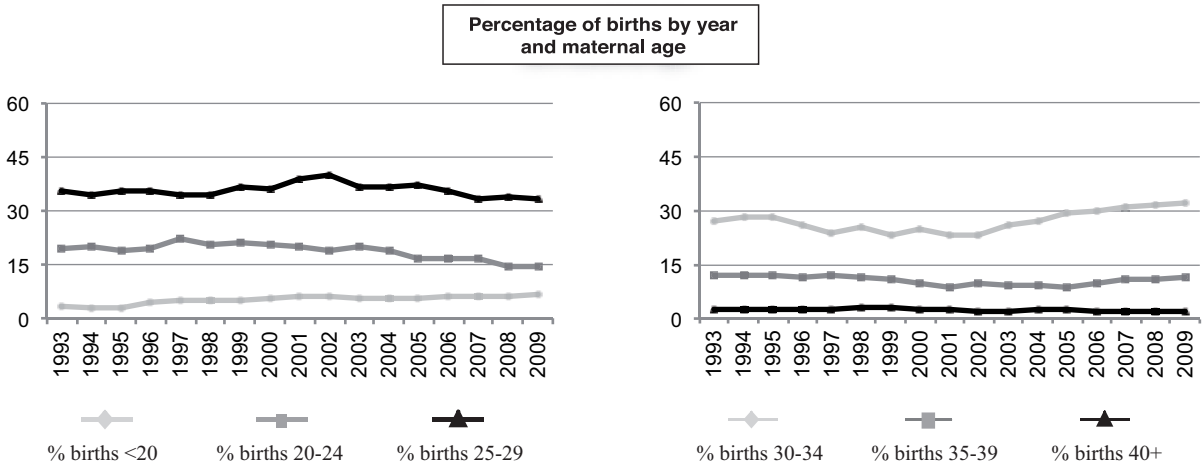
Malta Congenital Anomalies Registry
Department of Health Information and Research
95, Guardamangia Hill
Guardamangia PTA 1313, Malta
Phone: 356 25599000
Fax: 356 25599385
E-mail: miriam.gatt@gov.mt

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


Percentage of births by year and maternal age
60
45
30
15
0
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Malta: MCAR, 2009

Live births (LB)	4,152
Stillbirths (SB)	28
Total births	4,180
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		2.39
Spina bifida	4	0		9.57
Encephalocele	0	0		0.00
Microcephaly	0	1		2.39
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	1	0		2.39
Tetralogy of Fallot	2	0		4.78
Hypoplastic left heart syndrome	4	0		9.57
Coarctation of aorta	1	0		2.39
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	6	0		14.35
Cleft lip with or without cleft palate	1	0		2.39
Oesophageal atresia/stenosis with or without fistula	1	0		2.39
Small intestine atresia/stenosis	1	0		2.39
Anorectal atresia/stenosis	0	1		2.39
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	6	0		14.35
Epispadias	0	0		0.00
Indeterminate sex	1	0		2.39
Renal agenesis	1	0		2.39
Cystic kidney	2	1		7.18
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial (*)	12	0		28.71
Total Limb reduction defects (include unspecified)	1	0		2.39
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	0	0		0.00
Omphalocele	2	1		7.18
Gastroschisis	0	0		0.00
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	0		2.39
Trisomy 18	2	0		4.78
Down syndrome, all ages (include age unknown)	7	0		16.75
<20	0	0		0.00
20-24	0	0		0.00
25-29	0	0		0.00
30-34	4	0		30.01
35-39	1	0		20.70
40-44	2	0		263.16
45+	0	0		0.00
unknown	0	0		---

nr = not reported
(*) All polydactyly included

Malta: MCAR, Previous years rates 1993 - 2009

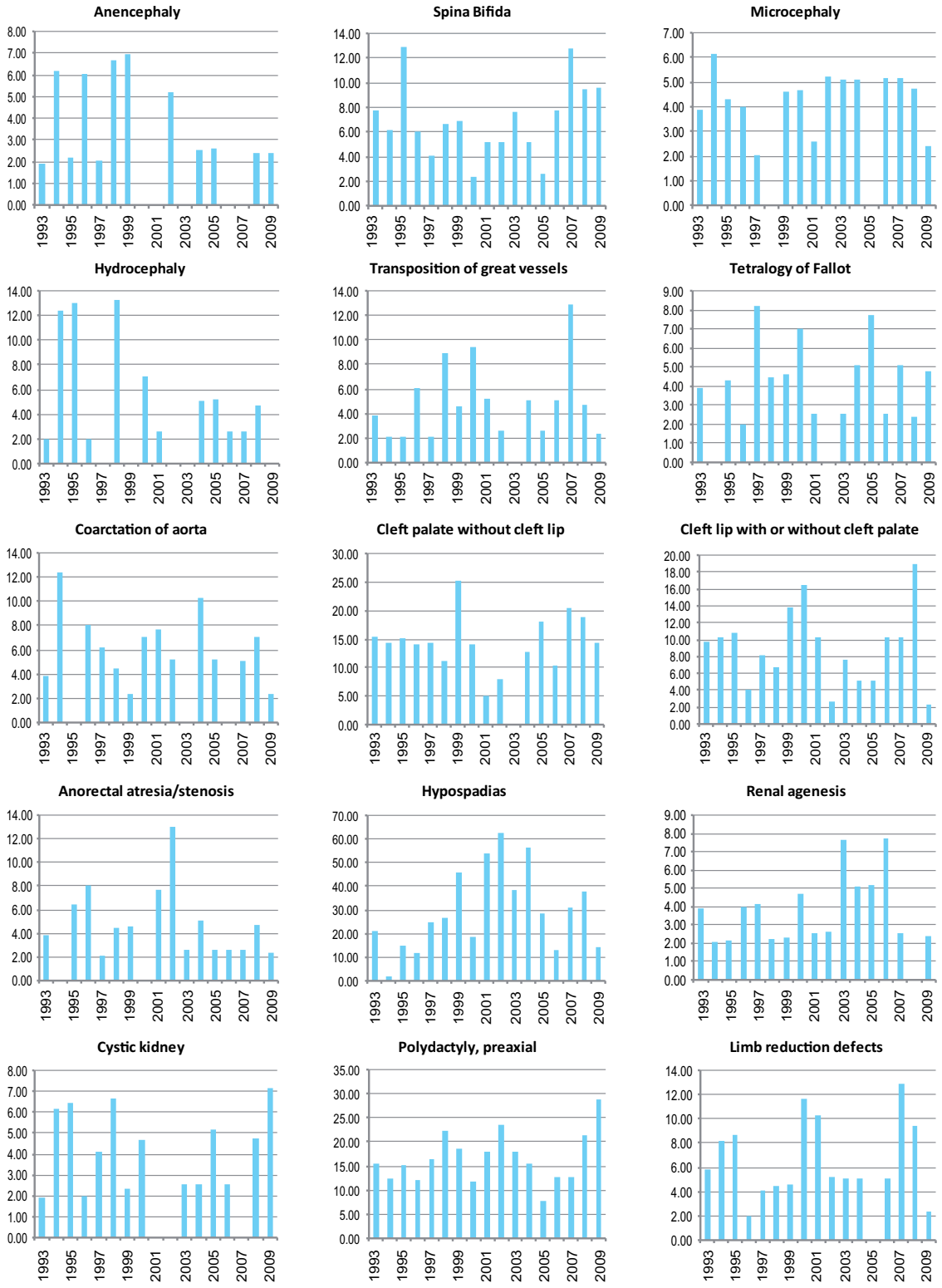
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994*	1995-1999	2000-2004	2005-2009
Total births				**10,035**	**23,325**	**19,803**	**20,062**
Anencephaly				3.99	4.72	1.51	1.50
Spina bifida				6.98	7.29	5.05	8.47
Encephalocele				1.99	1.71	2.02	1.99
Microcephaly				4.98	3.00	4.54	3.49
Holoprosencephaly				1.00	1.29	0.50	0.50
Hydrocephaly				6.98	5.57	3.03	2.99
Anophthalmos				1.00	0.00	0.00	0.00
Microphthalmos				0.00	1.71	1.01	0.00
Unspecified Anophthalmos/Microphthalmos				0.00	0.00	0.00	0.00
Anotia				0.00	0.00	0.00	0.00
Microtia				0.00	0.00	0.00	0.00
Unspecified Anotia/Microtia				0.00	0.00	0.00	0.00
Transposition of great vessels				2.99	4.72	4.54	5.48
Tetralogy of Fallot				1.99	4.72	3.53	4.49
Hypoplastic left heart syndrome				1.00	1.71	3.53	4.98
Coarctation of aorta				7.97	4.29	6.06	3.99
Choanal atresia, bilateral				1.99	1.29	1.01	0.50
Cleft palate without cleft lip				14.95	15.86	8.08	16.45
Cleft lip with or without cleft palate				9.97	8.57	8.58	9.47
Oesophageal atresia/stenosis with or without fistula				1.99	1.29	2.02	2.49
Small intestine atresia/stenosis				0.00	2.14	2.02	1.50
Anorectal atresia/stenosis				1.99	5.14	5.55	2.99
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				11.96	24.44	45.45	24.92
Epispadias				1.99	0.86	0.00	0.00
Indeterminate sex				1.99	0.86	1.01	2.49
Renal agenesis				2.99	3.00	4.54	3.49
Cystic kidney				3.99	4.29	2.02	3.99
Bladder exstrophy				0.00	0.00	0.00	0.00
Polydactyly, preaxial				13.95	16.72	17.17	16.95
Total Limb reduction defects (include unspecified)				6.98	4.72	7.57	5.98
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				3.99	6.43	4.04	4.98
Omphalocele				2.99	2.14	1.51	3.99
Gastroschisis				1.99	0.43	1.51	0.50
Unspecified Omphalocele/Gastroschisis				0.00	0.00	0.00	0.00
Prune belly sequence				1.00	0.43	0.00	0.00
Trisomy 13				0.00	0.00	1.01	1.00
Trisomy 18				1.00	3.86	5.05	2.99
Down syndrome, all ages (include age unknown)				21.92	16.29	19.19	19.94
<20				0.00	9.12	8.64	15.74
20-24				0.00	0.00	0.00	6.26
25-29				8.55	3.65	9.35	4.32
30-34				14.54	22.12	22.32	14.63
35-39				84.32	44.26	64.10	58.14
40-44				204.92	130.72	155.21	255.75
45+				0.00	400.00	0.00	800.00
unknown				---	---	---	---

nr = not reported
* data include less than 5 years

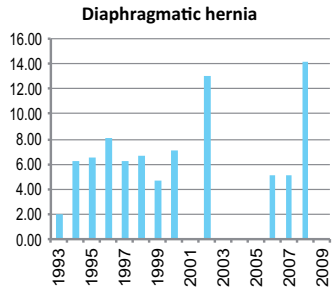
Malta: MCAR

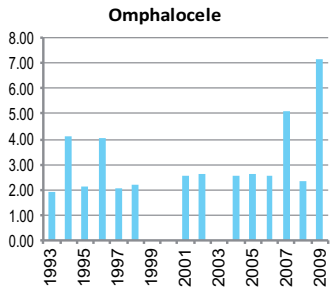
Time trends 1993-2009 (Birth prevalence rates per 10,000)

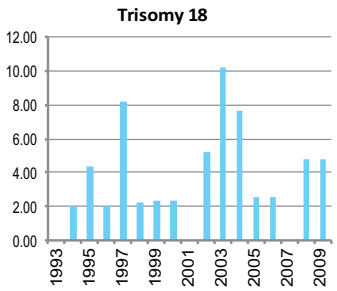


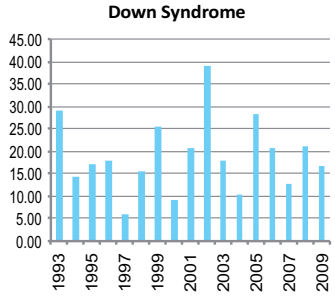
Note: L+S rates

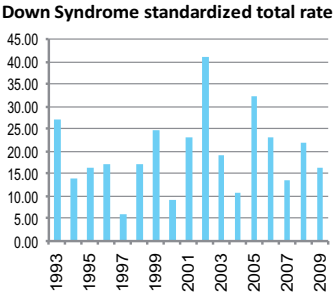
Malta: MCAR


Diaphragmatic hernia
16.00
14.00
12.00
10.00
8.00
6.00
4.00
2.00
0.00
1993
1995
1997
1999
2001
2003
2005
2007
2009


Omphalocele
8.00
7.00
6.00
5.00
4.00
3.00
2.00
1.00
0.00
1993
1995
1997
1999
2001
2003
2005
2007
2009


Trisomy 18
12.00
10.00
8.00
6.00
4.00
2.00
0.00
1993
1995
1997
1999
2001
2003
2005
2007
2009


Down Syndrome
45.00
40.00
35.00
30.00
25.00
20.00
15.00
10.00
5.00
0.00
1993
1995
1997
1999
2001
2003
2005
2007
2009


Down Syndrome standardized total rate
45.00
40.00
35.00
30.00
25.00
20.00
15.00
10.00
5.00
0.00
1993
1995
1997
1999
2001
2003
2005
2007
2009

Mexico: RYVEMCE

Mexican Registry and Epidemiological Surveillance of External Congenital Malformations

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

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

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

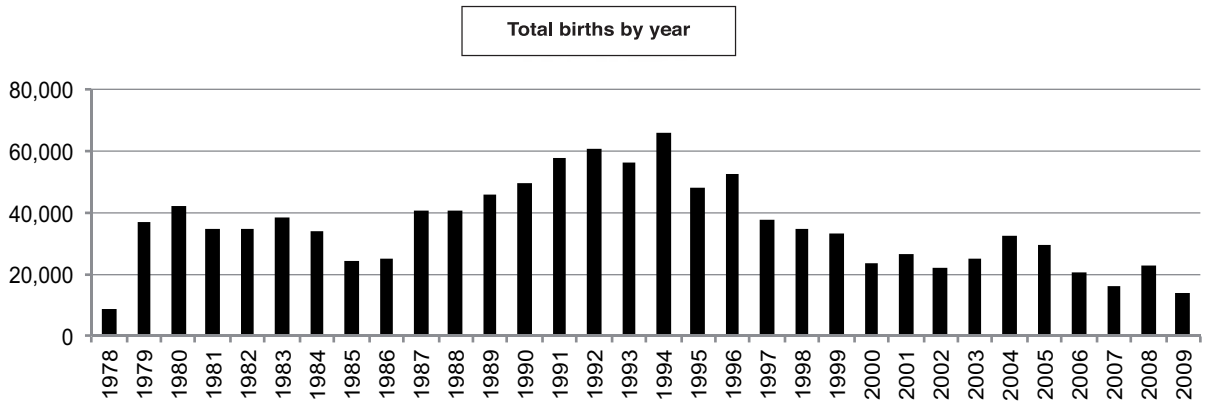
Sources of ascertainment:
Reports are obtained from the delivery units and pediatric departments of the participating hospitals.

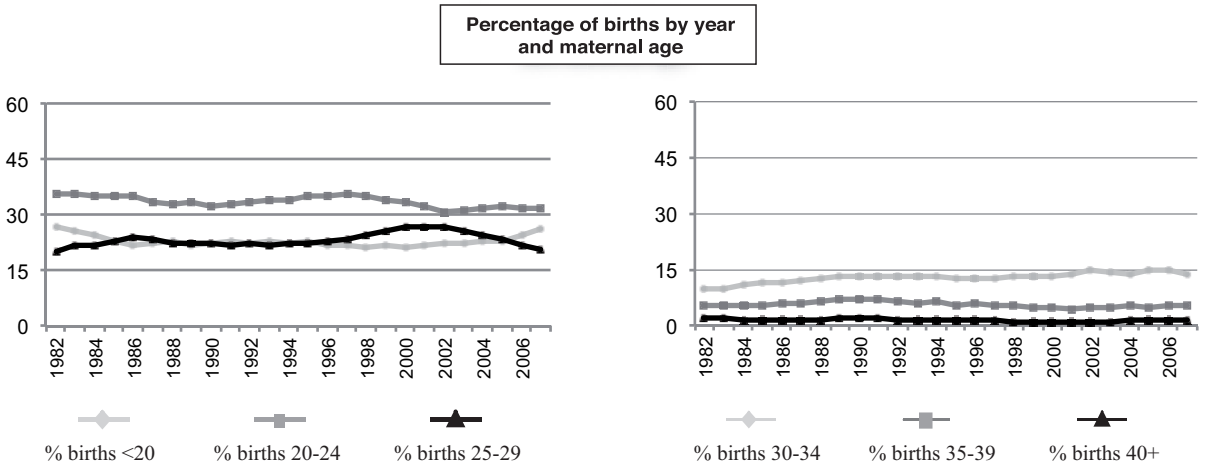
Exposure information:
The mother of each reported infant and the mother of a control infant-the next non-malformed infant born at that hospital with the same sex as the proband - are interviewed on various exposures, including drug usage and parental occupation.

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

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

Mexico: RYVEMCE





Mexico: RYVEMCE, 2009

Live births (LB)	13,211
Stillbirths (SB)	331
Total births	13,542
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	3		2.95
Spina bifida	7	0		5.17
Encephalocele	3	0		2.22
Microcephaly	2	0		1.48
Holoprosencephaly	3	2		3.69
Hydrocephaly	5	1		4.43
Anophthalmos	nr	nr		nr
Microphthalmos	nr	nr		nr
Unspecified Anophthalmos/Microphthalmos	3	2		3.69
Anotia	nr	nr		nr
Microtia	nr	nr		nr
Unspecified Anotia/Microtia	22	1		16.98
Transposition of great vessels	1	0		0.74
Tetralogy of Fallot	0	0		0.00
Hypoplastic left heart syndrome	0	0		0.00
Coarctation of aorta	1	0		0.74
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	2	0		1.48
Cleft lip with or without cleft palate	18	2		14.77
Oesophageal atresia/stenosis with or without fistula	2	1		2.22
Small intestine atresia/stenosis	3	0		2.22
Anorectal atresia/stenosis	7	0		5.17
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	5	0		3.69
Epispadias	0	0		0.00
Indeterminate sex	4	2		4.43
Renal agenesis	1	2		2.22
Cystic kidney	0	0		0.00
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	15	0		11.08
Total Limb reduction defects (include unspecified)	7	1		5.91
Transverse	2	0		1.48
Preaxial	2	1		2.22
Postaxial	1	0		0.74
Intercalary	1	0		0.74
Mixed	1	0		0.74
Unspecified	0	0		0.00
Diaphragmatic hernia	1	0		0.74
Omphalocele	0	1		0.74
Gastroschisis	8	1		6.65
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	0	0		0.00
Trisomy 18	0	1		0.74
Down syndrome, all ages (include age unknown)	25	1		19.20
<20	5	0		0.11
20-24	5	1		0.16
25-29	4	0		0.17
30-34	2	0		0.12
35-39	5	0		0.62
40+	4	0		3.47
unknown	0	0		---

nr = not reported

Mexico: RYVEMCE, Previous years rates 1980 - 2009

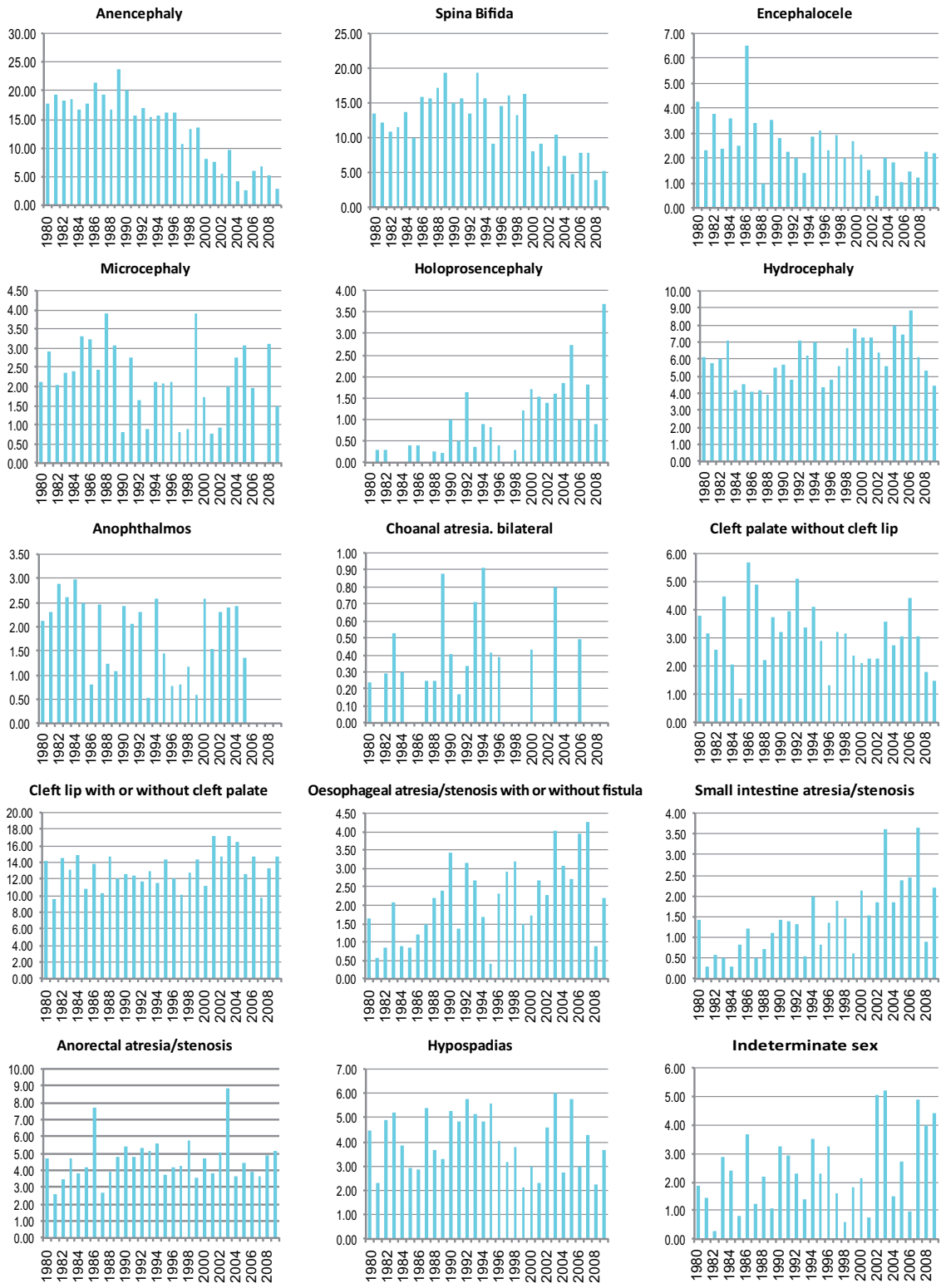
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**183,228**	**176,079**	**290,075**	**205,529**	**129,044**	**102,175**
Anencephaly		18.12	19.99	16.58	14.26	6.90	4.60
Spina bifida		12.39	16.19	15.82	13.62	8.21	5.77
Encephalocele		3.27	3.18	2.28	2.63	1.63	1.57
Microcephaly		2.35	3.18	1.69	1.95	1.70	2.15
Holoprosencephaly		0.11	0.23	0.90	0.54	1.63	1.96
Hydrocephaly		5.89	4.49	6.21	5.64	6.97	6.66
Anophthalmos		2.57	1.59	2.00	0.97	2.25	1.36
Microphthalmos		nr	nr	nr	nr	nr	nr
Unspecified Anophthalmos/Microphthalmos		nr	nr	nr	nr	nr	3.44
Anotia		nr	nr	nr	nr	nr	nr
Microtia		nr	nr	nr	nr	nr	nr
Unspecified Anotia/Microtia		6.77	6.42	6.55	6.47	8.99	9.59
Transposition of great vessels		0.05	0.11	0.14	0.19	0.31	0.78
Tetralogy of Fallot		0.00	0.00	0.17	0.19	0.23	0.20
Hypoplastic left heart syndrome		0.00	0.00	0.03	0.00	0.23	0.20
Coarctation of aorta		0.05	0.06	0.03	0.10	0.00	0.39
Choanal atresia, bilateral		0.27	0.34	0.52	0.19	0.23	0.10
Cleft palate without cleft lip		3.27	3.52	4.00	2.53	2.63	2.84
Cleft lip with or without cleft palate		13.26	12.32	12.20	12.75	15.50	13.02
Oesophageal atresia/stenosis with or without fistula		1.26	1.76	2.41	1.99	2.79	2.74
Small intestine atresia/stenosis		0.65	0.85	1.34	1.22	2.17	2.25
Anorectal atresia/stenosis		3.93	4.43	5.27	4.28	5.11	4.40
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr
Hypospadias		4.20	3.75	5.17	3.89	3.64	3.91
Epispadias		nr	nr	nr	nr	0.00	0.20
Indeterminate sex		1.80	1.70	2.69	2.04	2.79	3.23
Renal agenesis		0.38	0.40	0.66	0.39	0.54	1.37
Cystic kidney		0.33	0.57	0.90	0.78	1.78	0.78
Bladder exstrophy		0.49	0.40	0.45	0.44	0.23	0.10
Polydactyly, preaxial		11.84	13.80	12.20	12.65	13.41	9.30
Total Limb reduction defects (include unspecified)		6.11	6.87	6.07	5.16	6.66	5.97
Transverse		nr	nr	nr	nr	3.56	3.03
Preaxial		nr	nr	nr	nr	1.32	0.78
Postaxial		nr	nr	nr	nr	0.31	0.59
Intercalary		nr	nr	nr	nr	0.54	0.29
Mixed		nr	nr	nr	nr	0.85	0.88
Unspecified		nr	nr	nr	nr	0.08	0.39
Diaphragmatic hernia		0.55	0.80	1.10	0.92	1.32	1.08
Omphalocele		1.58	1.65	1.69	1.46	2.40	1.76
Gastroschisis		0.71	1.19	2.07	2.63	5.11	5.58
Unspecified Omphalocele/Gastroschisis		nr	nr	nr	nr	0.00	0.00
Prune belly sequence		1.20	1.08	1.07	0.73	0.70	0.29
Trisomy 13		0.33	0.34	0.14	0.15	0.31	0.88
Trisomy 18		0.65	0.57	0.38	0.15	0.31	0.78
Down syndrome, all ages (include age unknown)		12.88	13.01	14.44	12.21	10.85	12.33
<20		7.33	8.51	9.65	6.91	5.23	0.54
20-24		6.53	6.27	8.02	5.25	6.57	0.65
25-29		6.61	8.30	12.14	9.07	5.55	0.57
30-34		19.01	16.57	14.70	11.81	12.12	0.76
35-39		46.00	45.76	40.70	46.70	55.55	2.69
40-44		133.50	135.14	137.31	201.11	157.15	14.18
45+		137.46*	78.53*	226.93	176.47*	nr	123.46*
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

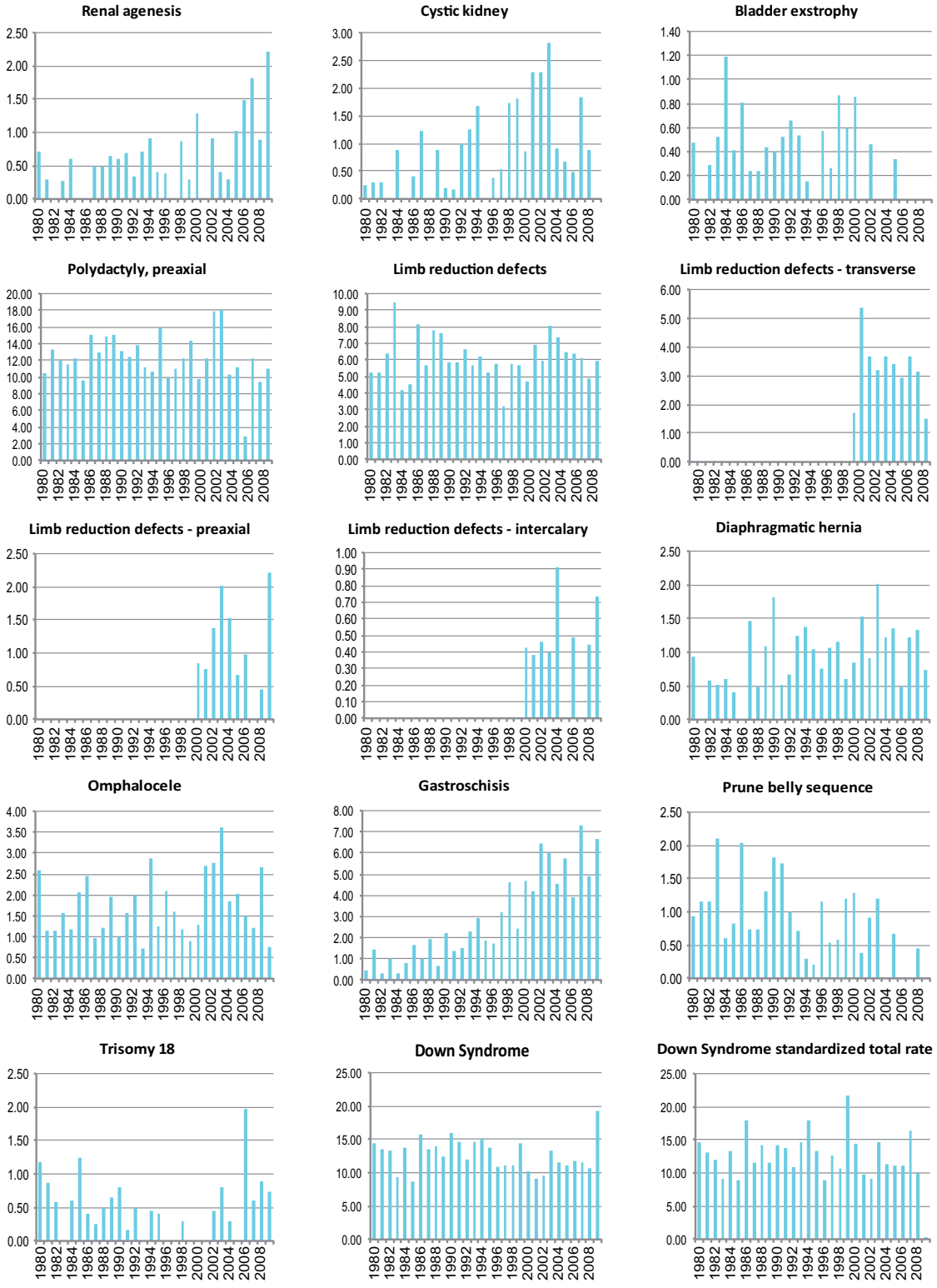
Mexico: RYVEMCE

Time trends 1980-2009 (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 includes all live and fetal deaths (stillbirths) with a diagnosed birth defect in New Zealand. Livebirths are those delivered or treated in a publicly funded hospital and only these data are included in the quarterly and annual reports to the ICBDSR. There is usually an 18 month delay in receiving data on fetal deaths from the national perinatal and infant mortality databases. A voluntary system of collecting data on birth defects present in terminations of pregnancy was implemented in February 2011.

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

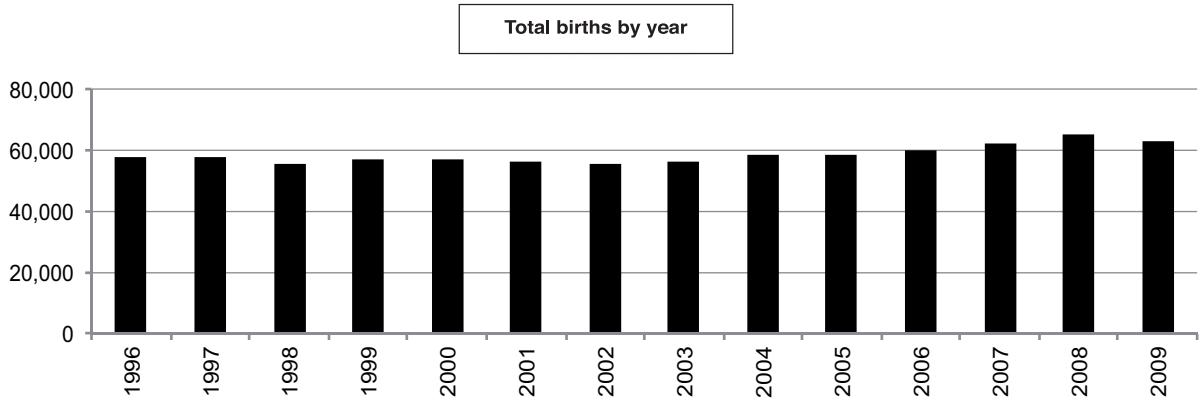
Sources of ascertainment:
Ascertainment is from discharge records of publicly funded hospitals, fetal death notification forms, and terminations of pregnancy.

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
Phone: +64-4-801-5799
Fax: +64-4-380-0600
E-mail: b.borman@massey.ac.nz
Website: www.nzbdr.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

New Zealand, 2009

Live births (LB)	62,543
Stillbirths (SB)	384
Total births	62,927
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	nr	nr	0.48
Spina bifida	9	nr	nr	1.43
Encephalocele	2	nr	nr	0.32
Microcephaly	17	nr	nr	2.70
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	21	nr	nr	3.34
Anophthalmos	0	nr	nr	0.00
Microphthalmos	3	nr	nr	0.48
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	29	nr	nr	4.61
Tetralogy of Fallot	29	nr	nr	4.61
Hypoplastic left heart syndrome	2	nr	nr	0.32
Coarctation of aorta	17	nr	nr	2.70
Choanal atresia, bilateral	9	nr	nr	1.43
Cleft palate without cleft lip	63	nr	nr	10.01
Cleft lip with or without cleft palate	48	nr	nr	7.63
Oesophageal atresia/stenosis with or without fistula	10	nr	nr	1.59
Small intestine atresia/stenosis	21	nr	nr	3.34
Anorectal atresia/stenosis	10	nr	nr	1.59
Undescended testis (36 weeks of gestation or later)	220	nr	nr	34.96
Hypospadias	134	nr	nr	21.29
Epispadias	nr	nr	nr	nr
Indeterminate sex	4	nr	nr	0.64
Renal agenesis	15	nr	nr	2.38
Cystic kidney	32	nr	nr	5.09
Bladder exstrophy	0	nr	nr	0.00
Polydactyly, preaxial	66	nr	nr	10.49
Total Limb reduction defects (include unspecified)	32	nr	nr	5.09
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	nr	nr	nr	nr
Omphalocele	28	nr	nr	4.45
Gastroschisis	7	nr	nr	1.11
Unspecified Omphalocele/Gastroschisis	6	nr	nr	0.95
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	3	nr	nr	0.48
Trisomy 18	4	nr	nr	0.64
Down syndrome, all ages (include age unknown)	49	nr	nr	7.79
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported

New Zealand, Previous years rates 1980 - 2009

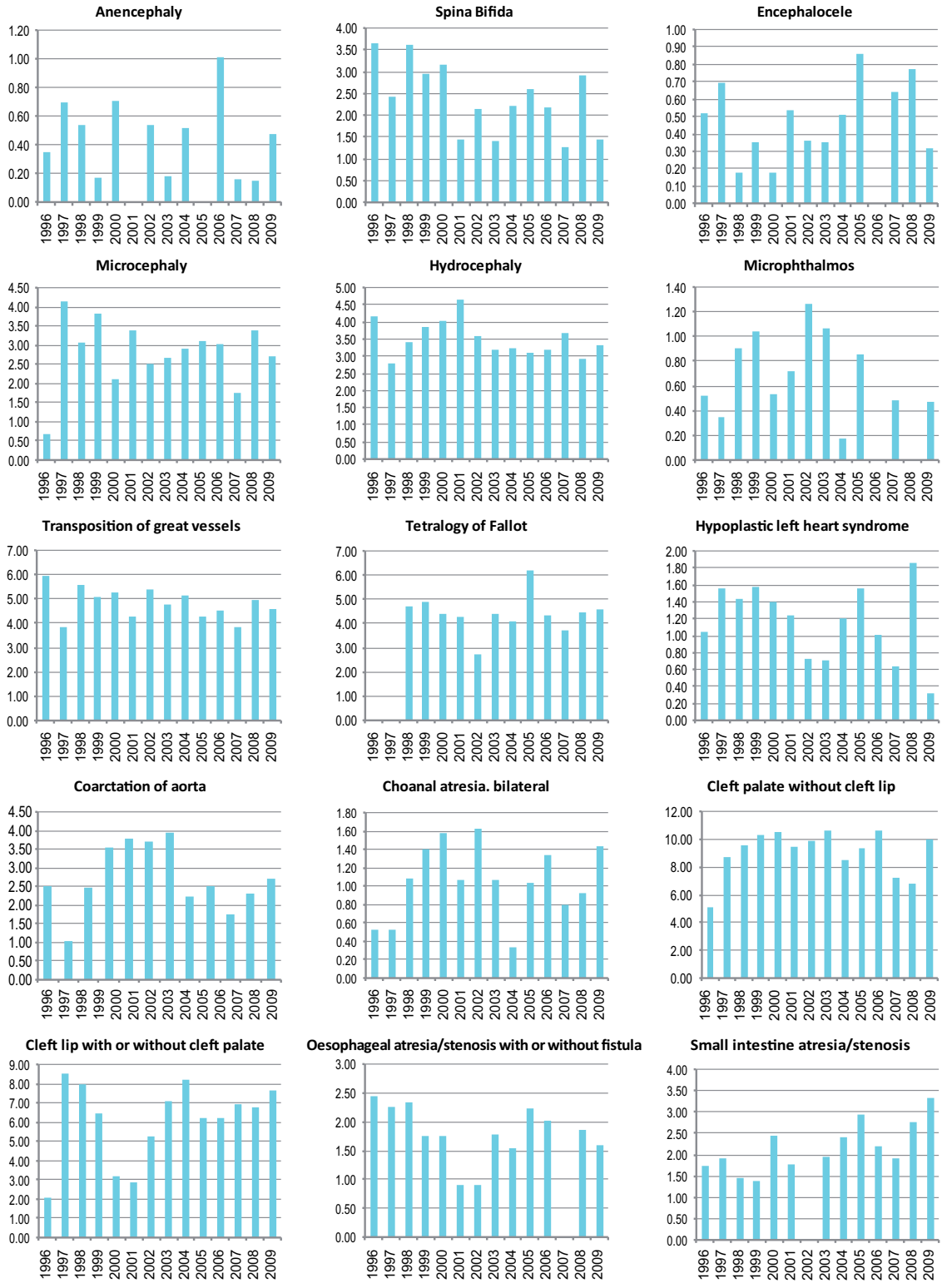
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**244,840**	**271,170**	**295,872**	**285,789**	**283,649**	**307,807**
Anencephaly		5.23	2.77	0.74	0.45	0.39	0.36
Spina bifida		11.15	6.64	4.02	3.04	2.08	2.08
Encephalocele		0.60*	0.75*	nr	0.35	0.39	0.52
Microcephaly		nr	nr	nr	2.94*	2.71	2.79
Holoprosencephaly		nr	nr	nr	nr	nr	nr
Hydrocephaly		4.33	3.65	2.50	3.43	3.74	3.25
Anophthalmos		nr	nr	nr	nr	0.04	0.16*
Microphthalmos		nr	nr	nr	0.70	0.74	0.44*
Unspecified Anophthalmos/Microphthalmos		nr	nr	nr	nr	0.00	0.25*
Anotia		nr	nr	nr	nr	nr	nr
Microtia		nr	nr	nr	nr	nr	nr
Unspecified Anotia/Microtia		nr	nr	nr	nr	nr	nr
Transposition of great vessels		nr	0.55*	nr	5.09*	4.97	4.45
Tetralogy of Fallot		nr	nr	nr	4.78*	3.98	4.65
Hypoplastic left heart syndrome		nr	0.82*	nr	1.50	1.06	1.07
Coarctation of aorta		nr	nr	nr	1.77*	3.49	2.31
Choanal atresia, bilateral		nr	nr	nr	0.88*	1.13	1.10
Cleft palate without cleft lip		6.37	7.38	5.27	7.52	9.80	8.74
Cleft lip with or without cleft palate		8.99	8.41	4.06	5.42	5.32	6.76
Oesophageal atresia/stenosis with or without fistula		1.67	1.81	2.57	2.06	1.37	1.91*
Small intestine atresia/stenosis		nr	nr	nr	1.62*	2.15*	2.63
Anorectal atresia/stenosis		2.33	2.47	2.87	2.34	2.22	2.40
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	62.32*	77.84	55.03
Hypospadias		13.15	13.39	11.66*	20.96*	29.68	26.09
Epispadias		nr	nr	nr	nr	nr	nr
Indeterminate sex		nr	nr	nr	0.47*	0.63	0.88
Renal agenesis		0.40*	0.33*	nr	3.52*	3.10	2.79
Cystic kidney		nr	nr	nr	5.61*	6.03	5.59
Bladder exstrophy		nr	nr	nr	0.35*	0.28	0.10
Polydactyly, preaxial		nr	nr	nr	5.99*	10.06*	15.17
Total Limb reduction defects (include unspecified)		3.72	3.10	2.43	2.41*	2.93	2.88*
Transverse		nr	nr	nr	nr	nr	nr
Preaxial		nr	nr	nr	nr	nr	nr
Postaxial		nr	nr	nr	nr	nr	nr
Intercalary		nr	nr	nr	nr	nr	nr
Mixed		nr	nr	nr	nr	nr	nr
Unspecified		nr	nr	nr	nr	nr	2.01*
Diaphragmatic hernia		1.39*	1.55*	nr	2.21*	2.54	2.54*
Omphalocele		2.72*	1.59	2.20	nr	nr	4.31*
Gastroschisis		0.05*	0.75*	nr	nr	nr	1.11*
Unspecified Omphalocele/Gastroschisis		nr	0.37*	nr	nr	nr	3.60*
Prune belly sequence		nr	nr	nr	nr	nr	nr
Trisomy 13		nr	nr	nr	0.44*	0.42	0.52
Trisomy 18		nr	nr	nr	0.88*	1.30	1.04
Down syndrome, all ages (include age unknown)		8.82	9.62	9.69*	10.22	11.49	9.65
<20		5.42	5.96*	nr	nr	nr	nr
20-24		4.50	3.68*	nr	nr	nr	nr
25-29		8.12	9.18*	nr	nr	nr	nr
30-34		10.46	8.28*	nr	nr	nr	nr
35-39		32.23	33.29*	nr	nr	nr	nr
40-44		86.39	232.36*	nr	nr	nr	nr
45+		138.89	147.06*	nr	nr	nr	nr
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

New Zealand

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



Note: L+S rates

New Zealand

Note: L+S rates

Northern Netherlands
EUROCAT Registration Northern Netherlands

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

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

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

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

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

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

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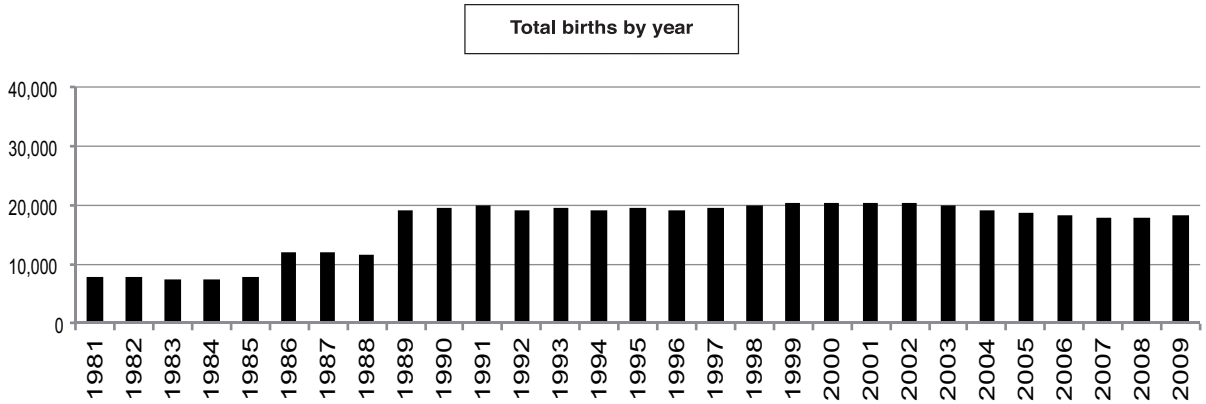
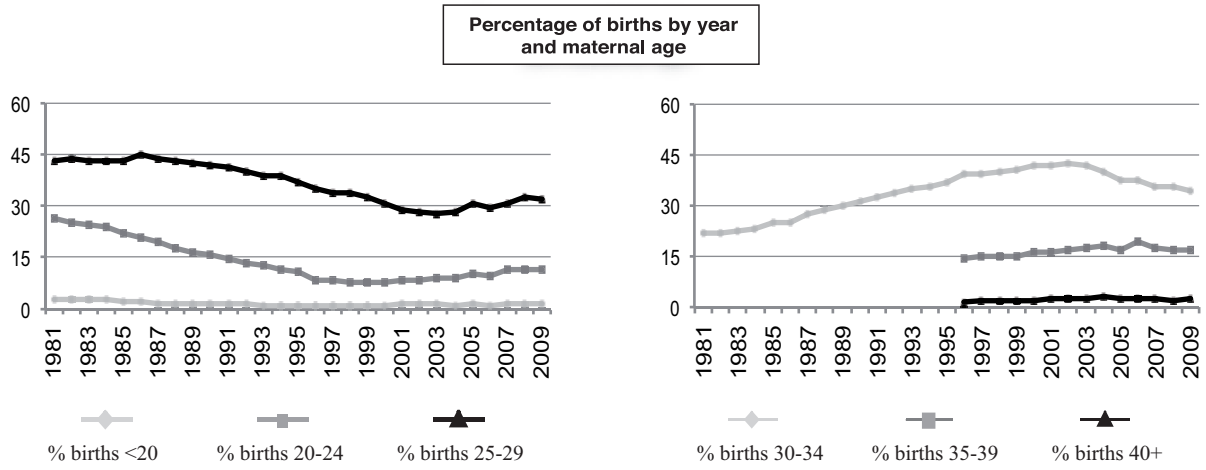
Northern Netherlands





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	14	93.3	Cystic kidney	14	40.0
Spina bifida	12	48.0	Limb reduction defects	5	19.2
Encephalocele	4	100.0	Diaphragmatic hernia	4	36.4
Holoprosencephaly	1	33.3	Omphalocele	7	58.3
Hydrocephaly	16	64.0	Gastroschisis	4	44.4
Hypoplastic left heart syndrome	9	56.3	Trisomy 13	10	76.9
Cleft palate without cleft lip	2	5.1	Trisomy 18	35	85.4
Cleft lip with or without cleft palate	5	7.7	Down syndrome	38	41.3
Renal agenesis	10	33.3			

Total ToPs with births defects = 199 (Ratio ToPs/Births: 3.70 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Northern Netherlands, 2009

Live births (LB)	18,041
Stillbirths (SB)	106
Total births	18,147
Number of terminations of pregnancy (ToP) for birth defects	76

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	7	3.86
Spina bifida	3	0	5	4.41
Encephalocele	0	0	3	1.65
Microcephaly	5	0	1	3.31
Holoprosencephaly	0	1	0	0.55
Hydrocephaly	3	1	4	4.41
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	1	1.10
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.55
Microtia	2	0	0	1.10
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	8	0	0	4.41
Tetralogy of Fallot	9	0	1	5.51
Hypoplastic left heart syndrome	2	0	2	2.20
Coarctation of aorta	7	0	1	4.41
Choanal atresia, bilateral	1	0	0	0.55
Cleft palate without cleft lip	14	0	1	8.27
Cleft lip with or without cleft palate	16	0	2	9.92
Oesophageal atresia/stenosis with or without fistula	0	0	0	0.00
Small intestine atresia/stenosis	4	0	0	2.20
Anorectal atresia/stenosis	10	0	1	6.06
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	24	1	0	13.78
Epispadias	3	0	0	1.65
Indeterminate sex	1	0	1	1.10
Renal agenesis	8	1	4	7.16
Cystic kidney	9	0	7	8.82
Bladder exstrophy	3	0	0	1.65
Polydactyly, preaxial	0	0	0	0.00
Total Limb reduction defects (include unspecified)	5	0	2	3.86
Transverse	3	0	2	2.76
Preaxial	2	0	1	1.65
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	1	0	1	1.10
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	4	1	1	3.31
Omphalocele	4	0	2	3.31
Gastroschisis	3	0	2	2.76
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	1	0.55
Trisomy 13	1	0	3	2.20
Trisomy 18	2	0	14	8.82
Down syndrome, all ages (include age unknown)	20	0	15	19.29
<20	0	0	0	0.00
20-24	1	0	0	4.72
25-29	2	0	2	6.87
30-34	9	0	4	20.66
35-39	6	0	6	38.77
40-44	2	0	0	42.19
45+	0	0	3	3,333.33
unknown	0	0	0	---

nr = not reported

Northern Netherlands, Previous years rates 1981 - 2009

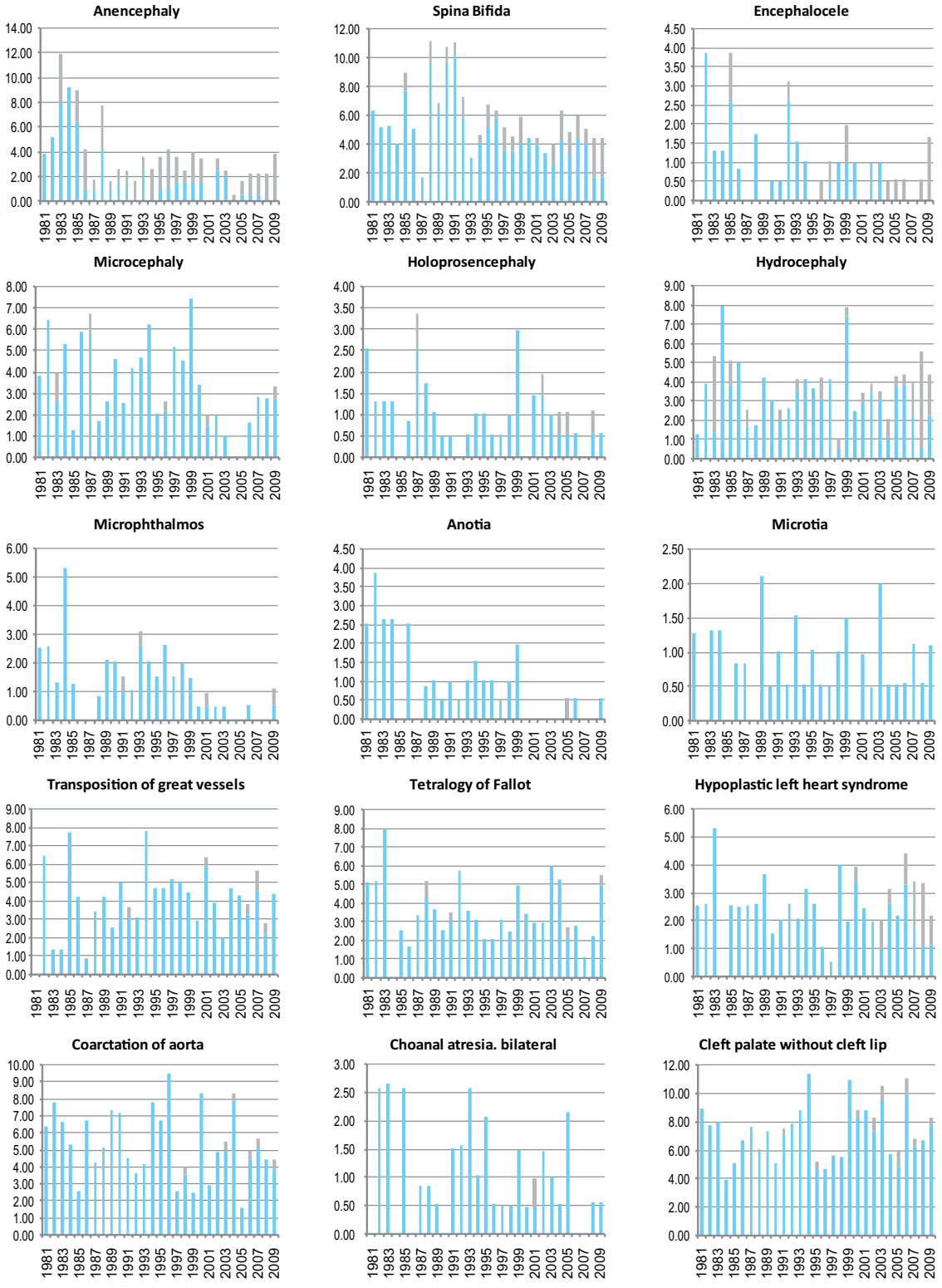
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984*	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**30,709**	**62,263**	**97,298**	**97,969**	**100,552**	**90,450**	
Anencephaly	7.49	4.18	2.57	3.57	1.99	2.43	
Spina bifida	5.21	6.58	7.40	5.72	4.48	4.98	
Encephalocele	1.63	0.96	1.34	0.92	0.70	0.66	
Microcephaly	4.88	3.69	4.42	4.39	1.69	2.10	
Holoprosencephaly	1.63	1.45	0.51	1.22	1.09	0.66	
Hydrocephaly	4.56	3.69	3.29	4.18	3.08	4.53	
Anophthalmos	0.00	0.32	0.41	0.10	0.00	0.00	
Microphthalmos	2.93	0.96	1.95	1.84	0.50	0.33	
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr	1.37*	1.65*	
Anotia	2.93	0.96	0.92	1.12	0.00	0.33	
Microtia	0.98	0.96	0.82	0.92	0.80	0.77	
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	
Transposition of great vessels	2.28	3.85	4.42	4.80	3.98	4.20	
Tetralogy of Fallot	4.56	3.37	3.70	2.96	4.08	2.87	
Hypoplastic left heart syndrome	2.61	2.89	2.26	2.04	2.69	3.10	
Coarctation of aorta	6.51	5.62	5.45	5.00	5.97	4.20	
Choanal atresia, bilateral	1.30	0.80	1.34	1.02	0.90	0.66	
Cleft palate without cleft lip	7.16	6.75	8.12	6.43	8.45	7.74	
Cleft lip with or without cleft palate	16.61	15.10	15.31	14.80	14.02	13.05	
Oesophageal atresia/stenosis with or without fistula	2.28	3.21	2.67	3.98	3.98	2.10	
Small intestine atresia/stenosis	2.93	2.89	2.36	2.76	1.69	1.99	
Anorectal atresia/stenosis	1.95	3.69	2.98	3.57	3.88	3.76	
Undescended testis (36 weeks of gestation or later)	0.00	0.32	0.00	0.00	0.00	0.00	
Hypospadias	17.58	9.64	10.07	13.98	19.59	20.34	
Epispadias	0.33	0.64	0.41	0.51	0.50	0.66	
Indeterminate sex	0.00	0.32	0.21	0.51	0.40	0.77	
Renal agenesis	3.26	4.66	4.32	4.49	5.17	5.20	
Cystic kidney	2.28	5.62	5.04	4.29	3.78	6.97	
Bladder exstrophy	0.33	0.16	0.21	0.10	0.40	0.55	
Polydactyly, preaxial	2.61	1.93	1.75	2.35	1.29	0.55	
Total Limb reduction defects (include unspecified)	9.44	5.46	7.30	5.41	6.46	5.09	
Transverse	5.86	2.73	4.11	3.16	3.98	3.87	
Preaxial	1.95	0.64	1.03	0.61	0.80	1.11	
Postaxial	0.98	0.64	1.85	1.12	0.20	0.00	
Intercalary	0.33	0.00	0.31	0.10	0.10	0.22	
Mixed	0.65	0.00	0.62	0.10	0.30	0.66	
Unspecified	nr	nr	nr	nr	nr	nr	
Diaphragmatic hernia	2.28	3.05	2.16	3.47	2.88	1.77	
Omphalocele	1.95	1.77	3.60	2.65	1.49	2.21	
Gastroschisis	0.98	0.96	0.31	1.02	0.90	1.44	
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	nr	nr	
Prune belly sequence	0.33	0.16	0.62	0.31	0.30	0.22	
Trisomy 13	0.33	1.12	1.64	0.82	1.19	1.88	
Trisomy 18	2.61	2.25	1.54	3.78	3.98	7.63	
Down syndrome, all ages (include age unknown)	10.75	15.10	13.67	15.62	16.11	16.92	
<20	0.00	0.00	0.00	0.00	0.00	0.00	
20-24	13.01	4.25	9.04	5.89	4.68	6.10	
25-29	3.76	14.78	5.86	7.38	9.99	7.46	
30-34	13.05	8.67	14.30	12.67	9.54	16.20	
35-39	30.85	50.38	36.07	38.33	32.00	35.04	
40-44	nr	nr	nr	100.60*	130.72	57.73	
45+	nr	nr	nr	217.39*	114.94	769.23	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

Northern Netherlands

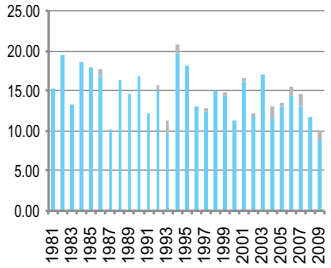
Time trends 1981-2009 (Birth prevalence rates per 10,000)



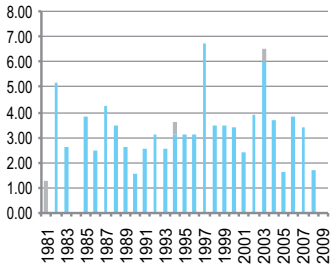
Note: L+S rates, ToP rates

Northern Netherlands

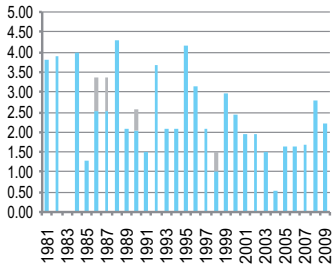
Cleft lip with or without cleft palate



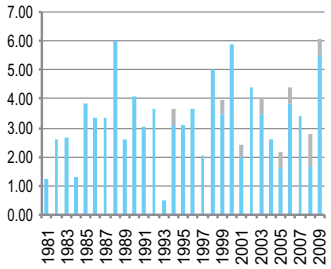
Oesophageal atresia/stenosis with or without fistula



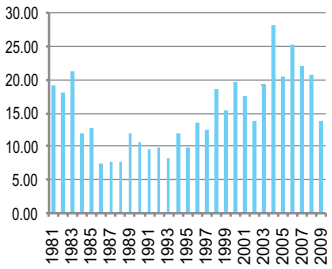
Small intestine atresia/stenosis



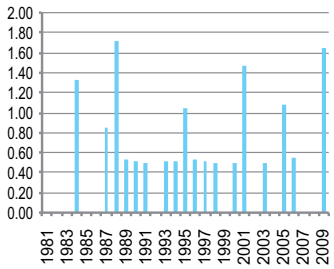
Anorectal atresia/stenosis



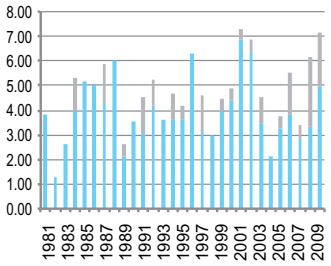
Hypospadias



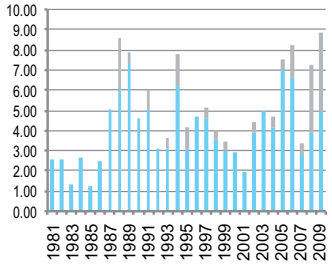
Epispadias



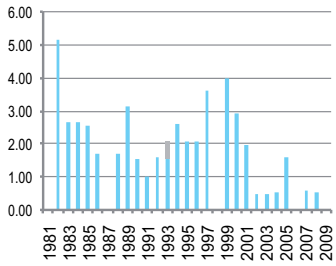
Renal agenesis



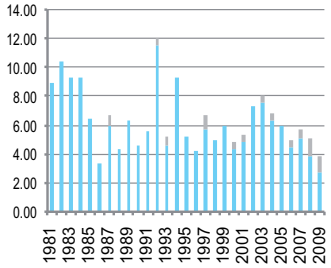
Cystic kidney



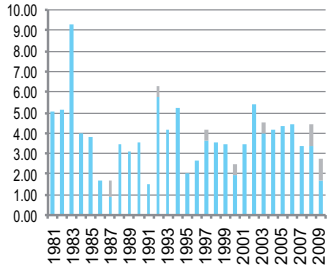
Polydactyly, preaxial



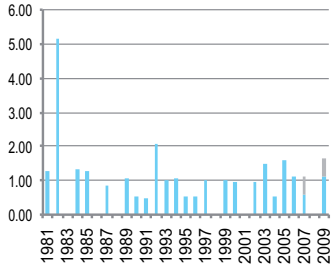
Limb reduction defects



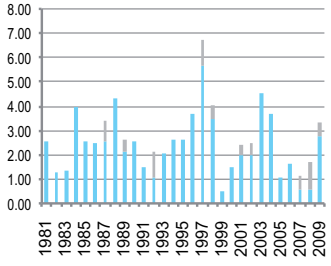
Limb reduction defects - transverse



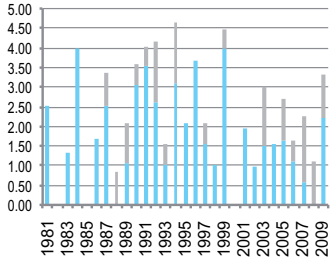
Limb reduction defects - preaxial



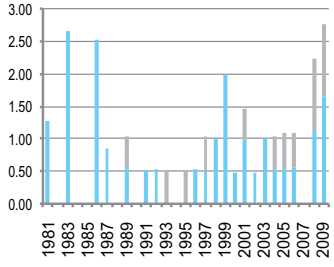
Diaphragmatic hernia



Omphalocele



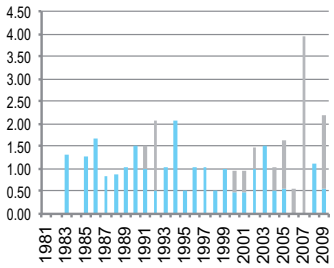
Gastroschisis



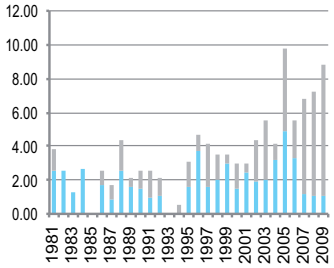
Note: L+S rates, ToP rates

Northern Netherlands

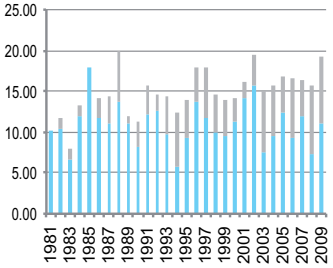
Trisomy 13



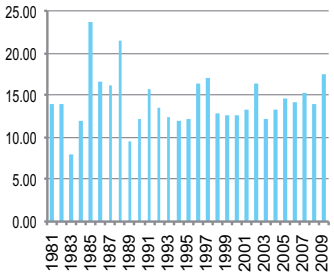
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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

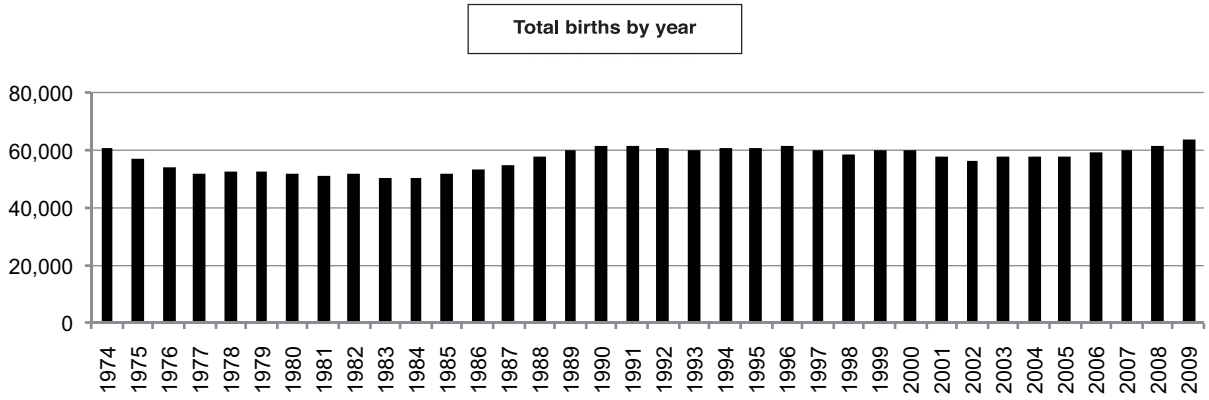
Sources of ascertainment:
The registry is based on the notification of births from the delivery units and since 1999 also from the neonatal units.

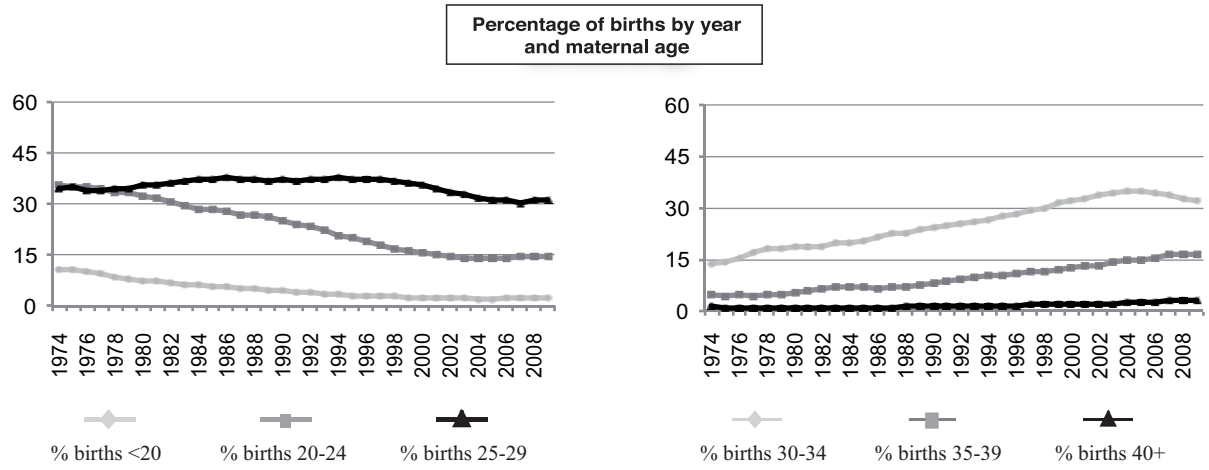
Exposure information:
Some basic information, such as maternal disease and since 1999, smoking and occupation, is collected on all infants, malformed or not.

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

Addresses and Staff:
Tone Bjørge, MD, Programme director
Medical Birth Registry of Norway
Norwegian Institute of Public Health
Kalfarveien 31
N-5018 Bergen, Norway
Phone: 47-53 20 4002
Fax: 47-53 20 4001
E-mail: tone.bjorge@isf.uib.no

Norway: MBRN





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	60	92.3	Cystic kidney	43	47.8
Spina bifida	65	65.0	Limb reduction defects	31	37.3
Encephalocele	17	77.3	Diaphragmatic hernia	14	24.6
Holoprosencephaly	26	86.7	Omphalocele	36	63.2
Hydrocephaly	36	42.4	Gastroschisis	8	11.9
Hypoplastic left heart syndrome	36	48.6	Trisomy 13	34	77.3
Cleft palate without cleft lip	6	5.1	Trisomy 18	56	65.1
Cleft lip with or without cleft palate	29	12.5	Down syndrome	130	41.3
Renal agenesis	26	76.5			

Total ToPs with births defects = 770 (Ratio ToPs/Births: 4.17 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Norway: MBRN, 2008

Live births (LB)	62,786
Stillbirths (SB)	272
Total births	63,313
Number of terminations of pregnancy (ToP) for birth defects	255

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	23	3.95
Spina bifida	12	0	21	5.21
Encephalocele	1	0	10	1.74
Microcephaly	2	0	2	0.63
Holoprosencephaly	3	0	8	1.74
Hydrocephaly	18	0	14	5.05
Anophthalmos	0	0	1	0.16
Microphthalmos	3	0	0	0.47
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.16
Microtia	1	0	0	0.16
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	25	0	7	5.05
Tetralogy of Fallot	18	0	3	3.32
Hypoplastic left heart syndrome	10	1	11	3.47
Coarctation of aorta	15	1	5	3.32
Choanal atresia, bilateral	3	0	0	0.47
Cleft palate without cleft lip	47	0	1	7.58
Cleft lip with or without cleft palate	67	1	8	12.00
Oesophageal atresia/stenosis with or without fistula	12	0	0	1.90
Small intestine atresia/stenosis	5	0	1	0.95
Anorectal atresia/stenosis	18	1	6	3.95
Undescended testis (36 weeks of gestation or later)	130	0	0	20.53
Hypospadias	64	0	0	10.11
Epispadias	2	0	1	0.47
Indeterminate sex	5	0	0	0.79
Renal agenesis	1	0	8	1.42
Cystic kidney	12	0	17	4.58
Bladder exstrophy	1	0	1	0.32
Polydactyly, preaxial	51	0	5	8.84
Total Limb reduction defects (include unspecified)	20	0	9	4.58
Transverse	10	0	4	2.21
Preaxial	4	0	2	0.95
Postaxial	1	0	1	0.32
Intercalary	1	0	0	0.16
Mixed	7	0	6	2.05
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	17	0	5	3.47
Omphalocele	9	0	13	3.47
Gastroschisis	20	0	1	3.32
Unspecified Omphalocele/Gastroschisis	2	0	2	0.63
Prune belly sequence	4	0	11	2.37
Trisomy 13	3	0	7	1.58
Trisomy 18	5	2	17	3.79
Down syndrome, all ages (include age unknown)	82	2	40	19.59
<20	2	0	0	12.96
20-24	4	0	3	7.47
25-29	17	1	0	9.14
30-34	21	0	7	13.79
35-39	29	1	17	44.93
40-44	8	0	13	113.27
45+	1	0	0	116.28
unknown	0	0	0	---

nr = not reported

Norway: MBRN, Previous years rates 1974 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**327,455**	**255,156**	**276,487**	**304,426**	**300,250**	**289,341**	**301,876**
Anencephaly	4.12	3.29	2.21	1.94	3.06	4.56	3.54
Spina bifida	4.83	5.72	4.77	3.88	4.90	4.77	5.47
Encephalocele	0.40	0.82	0.54	0.56	0.57	1.24	1.09
Microcephaly	0.70	0.55	0.61	0.56	0.83	0.41	0.63
Holoprosencephaly	0.03	0.27	0.43	0.59	1.10	0.73	1.42
Hydrocephaly	4.24	3.49	3.36	3.32	3.70	4.84	5.20
Anophthalmos	0.00	0.16	0.18	0.10	0.07	0.03	0.23
Microphthalmos	0.12	0.27	0.29	0.30	0.23	0.38	0.53
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.12	0.27	0.14	0.20	0.13	0.24	0.23
Microtia	nr	nr	1.47*	0.53	0.43	0.55	0.43
Unspecified Anotia/Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.40	0.74	1.56	1.84	2.43	3.25	4.54
Tetralogy of Fallot	0.12	0.27	0.51	1.08	1.57	2.80	2.58
Hypoplastic left heart syndrome	nr	nr	0.70*	1.64	2.20	3.11	3.41
Coarctation of aorta	0.38	0.47	0.69	0.92	1.13	2.21	3.54
Choanal atresia, bilateral	0.21	0.43	0.65	0.43	0.40	0.66	0.83
Cleft palate without cleft lip	4.61	5.09	5.71	5.12	5.93	6.22	7.19
Cleft lip with or without cleft palate	14.08	14.03	14.76	13.21	12.99	12.72	13.35
Oesophageal atresia/stenosis with or without fistula	2.05	1.72	2.17	2.43	1.90	2.66	2.82
Small intestine atresia/stenosis	0.86	1.25	1.05	1.45	1.60	0.86	0.96
Anorectal atresia/stenosis	1.50	2.08	2.28	2.56	2.00	2.73	3.64
Undescended testis (36 weeks of gestation or later)	18.14	14.85	15.08	18.07	15.95	28.03	24.91
Hypospadias	12.73	13.76	16.17	15.96	14.52	16.38	13.38
Epispadias	0.27	0.35	0.47	0.16	0.33	0.24	0.13
Indeterminate sex	2.23	3.96	3.98	5.45	7.26	0.45	0.43
Renal agenesis	0.12	0.78	1.34	1.41	1.53	1.00	1.69
Cystic kidney	0.46	0.82	1.70	2.43	3.10	4.77	5.33
Bladder exstrophy	0.24	0.55	0.29	0.20	0.40	0.24	0.33
Polydactyly, preaxial	nr	nr	nr	nr	8.50*	8.19	9.18
Total Limb reduction defects (include unspecified)	8.83	6.47	7.34	6.50	6.66	3.84	4.70
Transverse	nr	nr	2.68*	3.61	3.03	2.04	2.32
Preaxial	nr	nr	0.84*	0.66	0.37	0.59	0.66
Postaxial	nr	nr	1.00*	0.56	0.40	0.07	0.17
Intercalary	nr	nr	0.17*	0.33	0.53	0.03	0.17
Mixed	nr	nr	0.00*	0.62	1.33	1.38	1.95
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	1.92	2.39	2.53	2.37	2.93	2.49	2.75
Omphalocele	2.38	2.04	2.03	2.00	2.10	2.25	2.88
Gastroschisis	1.25	1.69	1.74	2.14	2.93	2.32	3.48
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr	1.00*	0.45	0.60
Prune belly sequence	nr	nr	nr	nr	1.50*	1.28	2.09
Trisomy 13	nr	nr	nr	nr	1.00*	1.28	2.39
Trisomy 18	nr	nr	nr	nr	1.67*	3.63	4.84
Down syndrome, all ages (include age unknown)	9.80	9.76	11.32	10.12	12.99	17.04	17.76
<20	1.90	4.00	5.46	0.86	5.97	5.82	4.30
20-24	6.21	6.16	8.00	5.24	3.34	6.11	5.99
25-29	8.09	6.70	6.12	6.81	6.85	7.52	8.13
30-34	10.48	13.20	13.81	11.78	10.78	13.48	13.07
35-39	37.32	31.18	39.10	22.81	37.59	42.67	44.98
40-44	134.91	76.30	62.69	83.99	128.38	139.30	142.84
45+	161.29	185.19	315.79	322.58	198.68	319.63	225.35
unknown	---	---	---	---	---	---	---

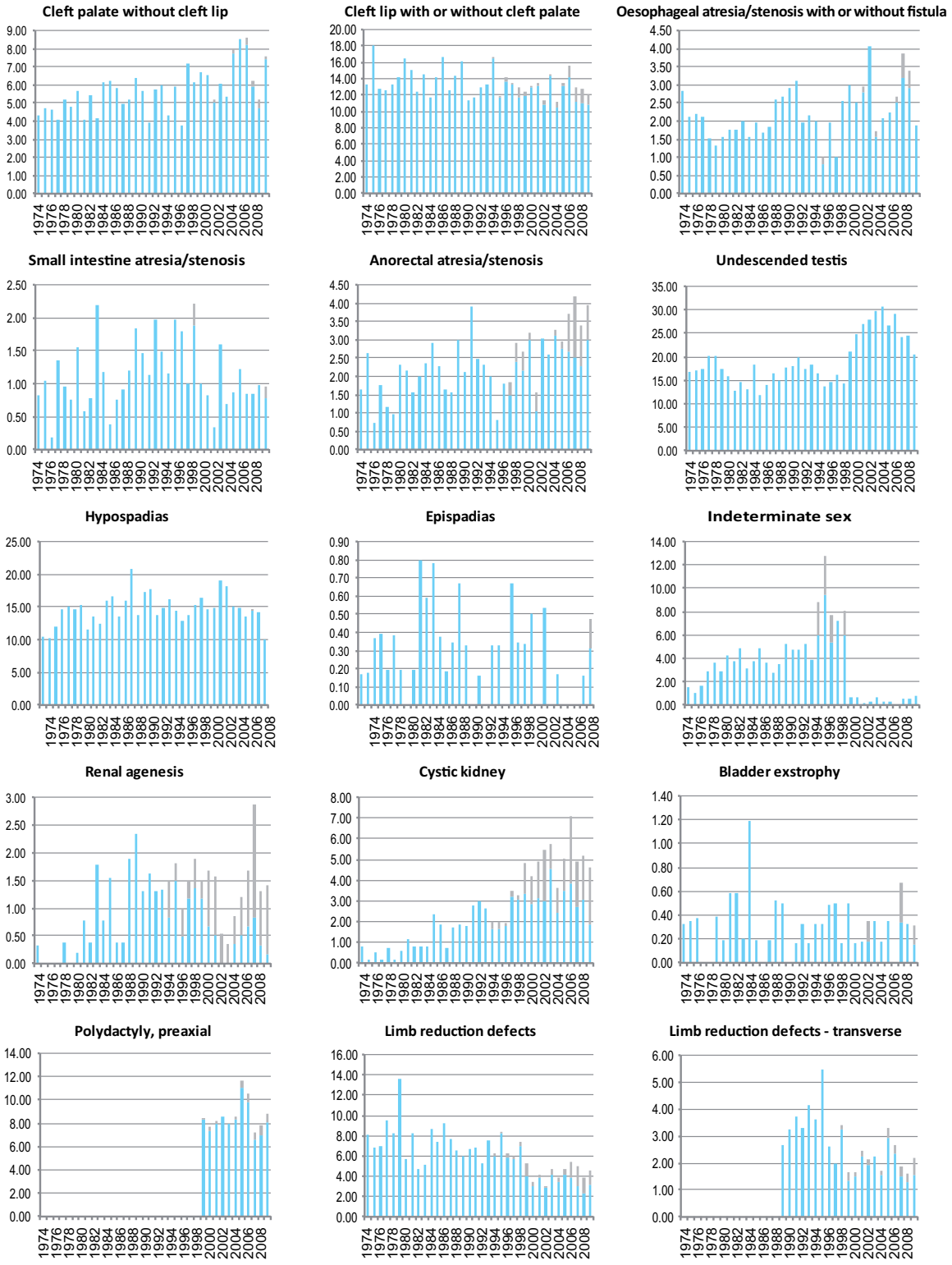
nr = not reported
* data include less than 5 years

Norway: MBRN

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

Note: L+S rates, ToP rates

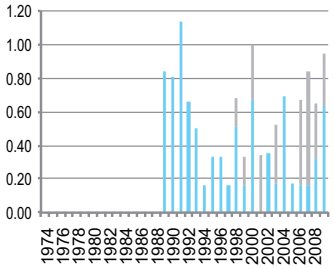
Norway: MBRN



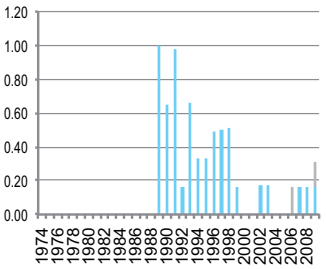
Note: L+S rates, ToP rates

Norway: MBRN

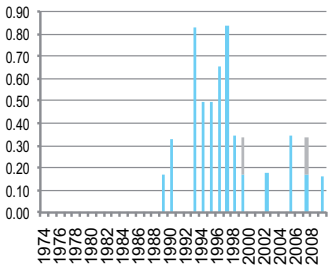
Limb reduction defects - preaxial



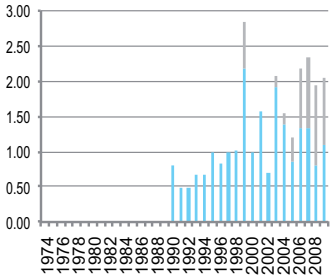
Limb reduction defects - postaxial



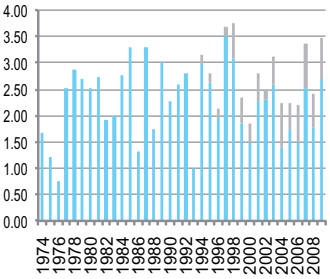
Limb reduction defects - intercalary



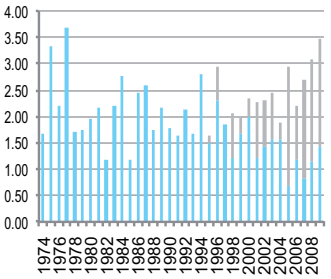
Limb reduction defects - mixed



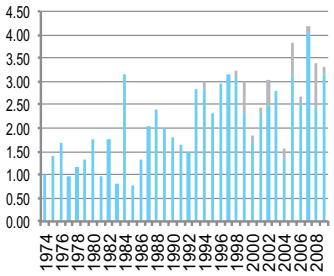
Diaphragmatic hernia



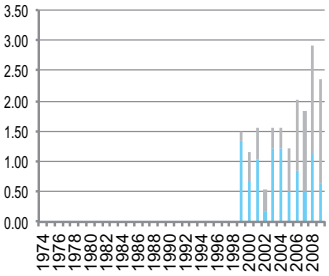
Omphalocele



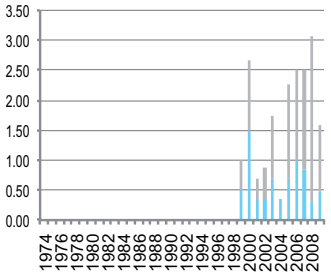
Gastroschisis



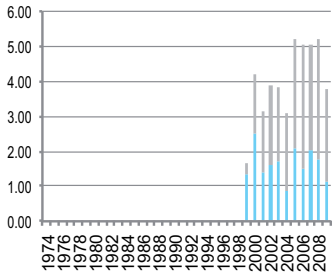
Prune belly sequence



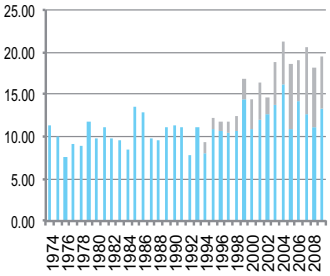
Trisomy 13



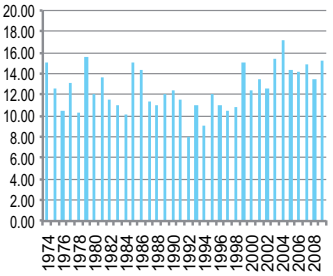
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Russia - Moskow Region: MRRCM

Moscow Regional Registry of Congenital Malformation

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

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

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

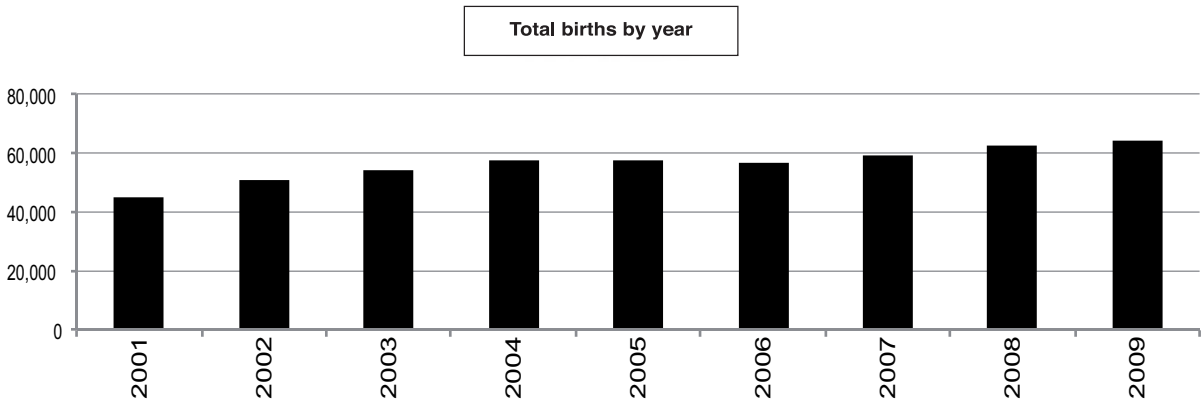
Sources of ascertainment:
Reporting is made by neonatologist during the first week of the infant's life in maternity hospitals and by pediatricians during the first year – in pediatric clinics and departments. Reports are collected from cytogenetic laboratories, pathology departments.

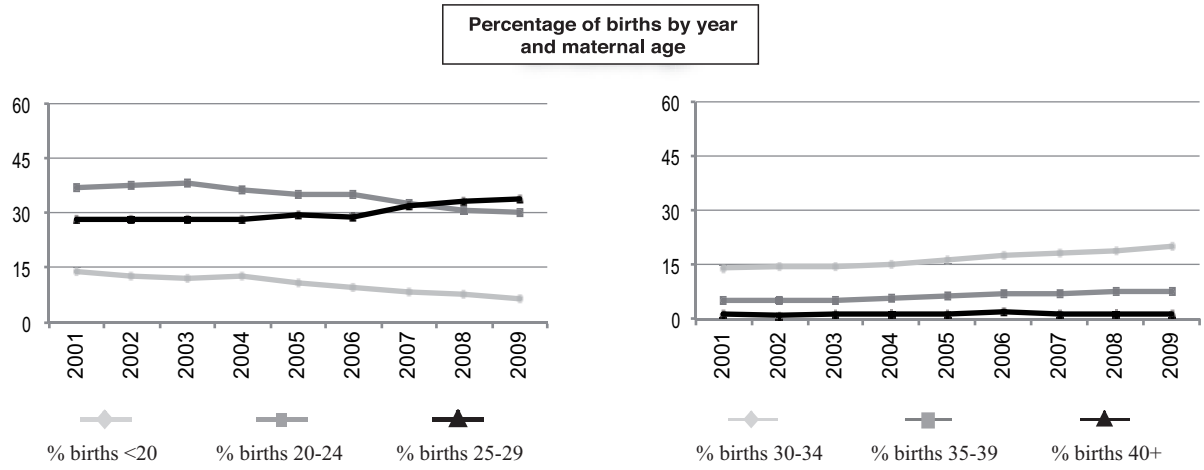
Exposure information:
No exposure information is routinely collected in the registry.

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

Addresses and Staff:
Ludmila Joutchenko, MD, Programme Director
Moscow Regional Research Scientific Institute of Obstetrics and Gynecology
22a, Pokrovka St.
101000 Moscow Russia
Phone: 007-0959356228
Fax: 007-0959215398
E-mail: mrrcm@mail.ru

Russia: MRRCM





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	38	82.6	Cystic kidney	14	25.9
Spina bifida	26	31.3	Limb reduction defects	8	15.4
Encephalocele	8	57.1	Diaphragmatic hernia	8	25.8
Holoprosencephaly	9	75.0	Omphalocele	14	31.8
Hydrocephaly	34	36.6	Gastroschisis	29	37.7
Hypoplastic left heart syndrome	9	36.0	Trisomy 13	0	0.0
Cleft palate without cleft lip	4	4.8	Trisomy 18	6	31.6
Cleft lip with or without cleft palate	10	8.7	Down syndrome	42	13.9
Renal agenesis	8	29.6			

Total ToPs with births defects = 664 (Ratio ToPs/Births: 3.57 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Russia: MRRCM, 2009

Live births (LB)	63,713
Stillbirths (SB)	291
Total births	64,004
Number of terminations of pregnancy (ToP) for birth defects	242

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	22	3.44
Spina bifida	11	0	7	2.81
Encephalocele	0	0	5	0.78
Microcephaly	1	0	3	0.62
Holoprosencephaly	1	0	2	0.47
Hydrocephaly	9	0	14	3.59
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	1	0	0	0.16
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	1	1.25
Tetralogy of Fallot	8	0	1	1.41
Hypoplastic left heart syndrome	0	0	2	0.31
Coarctation of aorta	2	0	0	0.31
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	27	0	3	4.69
Cleft lip with or without cleft palate	45	0	4	7.66
Oesophageal atresia/stenosis with or without fistula	13	0	2	2.34
Small intestine atresia/stenosis	10	0	0	1.56
Anorectal atresia/stenosis	6	0	1	1.09
Undescended testis (36 weeks of gestation or later)	100	0	0	15.62
Hypospadias	100	0	0	15.62
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	5	0	1	0.94
Cystic kidney	1	0	0	0.16
Bladder exstrophy	1	0	0	0.16
Polydactyly, preaxial	11	0	0	1.72
Total Limb reduction defects (include unspecified)	9	0	4	2.03
Transverse	5	0	2	1.09
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	3	0	2	0.78
Unspecified	1	0	0	0.16
Diaphragmatic hernia	2	1	2	0.78
Omphalocele	7	2	2	1.72
Gastroschisis	10	0	10	3.12
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	3	0	0	0.47
Trisomy 18	7	0	3	1.56
Down syndrome, all ages (include age unknown)	92	3	14	17.03
<20	2	0	0	4.85
20-24	19	0	2	10.84
25-29	25	2	4	14.19
30-34	12	0	0	9.33
35-39	26	0	4	60.79
40-44	7	1	4	143.03
45+	1	0	0	263.16
unknown	0	0	0	---

nr = not reported

Russia: MRRCM, Previous years rates 2001 - 2009

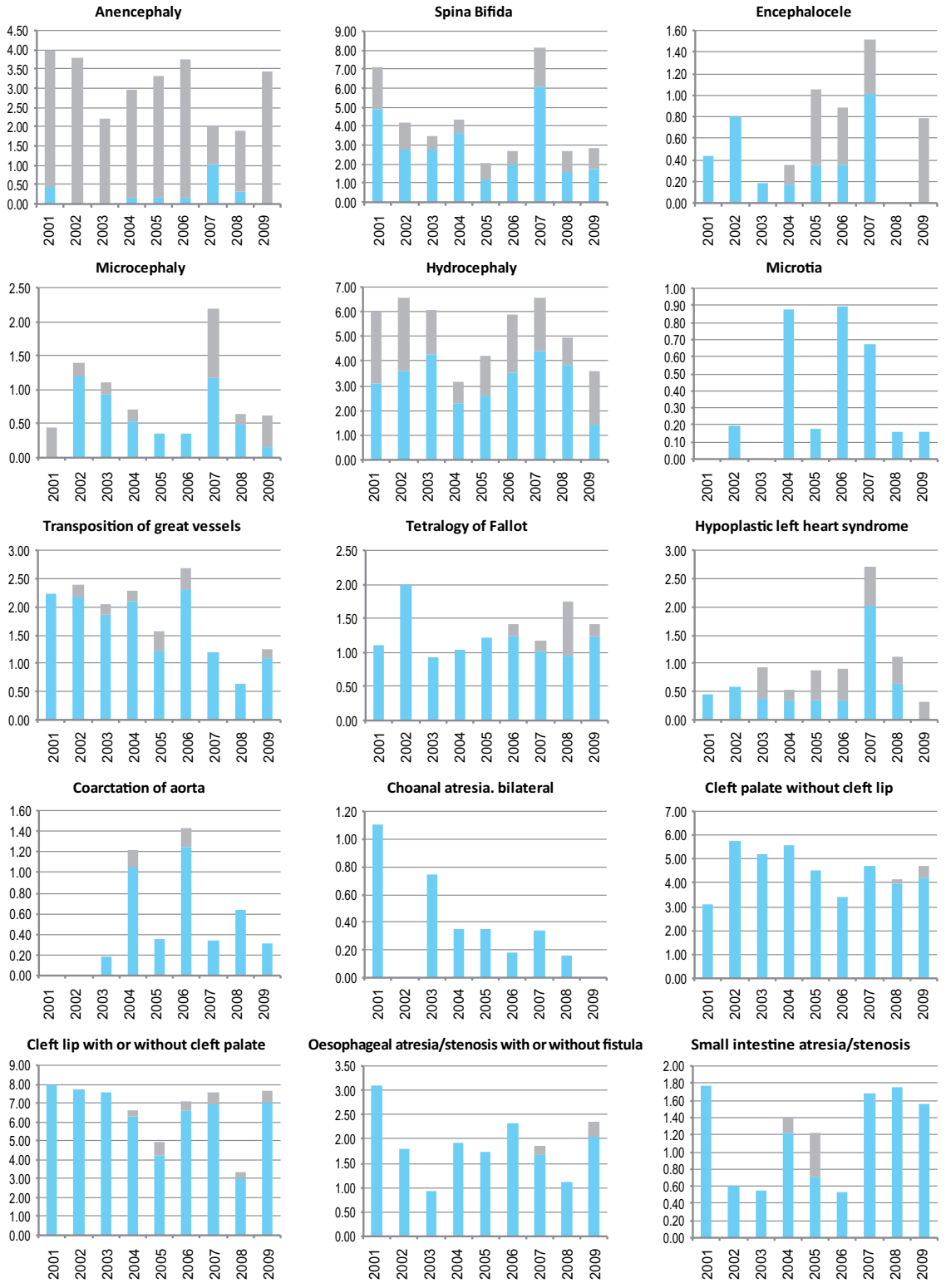
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004*	2005-2009
Total births						**206,687**	**299,201**
Anencephaly						3.19	2.87
Spina bifida						4.69	3.68
Encephalocele						0.44	1.06*
Microcephaly						0.92	0.84
Holoprosencephaly						0.15	0.50
Hydrocephaly						5.37	5.01
Anophthalmos						0.15	0.07
Microphthalmos						0.10	0.08*
Unspecified Anophthalmos/Microphthalmos						0.00	0.00
Anotia						0.05	0.33
Microtia						0.29	0.40
Unspecified Anotia/Microtia						0.68	0.00
Transposition of great vessels						2.23	1.44
Tetralogy of Fallot						1.26	1.40
Hypoplastic left heart syndrome						0.63	1.17
Coarctation of aorta						0.39	0.60
Choanal atresia, bilateral						0.53	0.20
Cleft palate without cleft lip						4.98	4.31
Cleft lip with or without cleft palate						7.45	6.12
Oesophageal atresia/stenosis with or without fistula						1.89	1.87
Small intestine atresia/stenosis						1.06	1.37
Anorectal atresia/stenosis						2.32	1.84
Undescended testis (36 weeks of gestation or later)						21.48	14.34
Hypospadias						15.29	14.61
Epispadias						0.15	0.17
Indeterminate sex						0.48	0.38*
Renal agenesis						1.50	1.57
Cystic kidney						2.90	2.74
Bladder exstrophy						0.15	0.17*
Polydactyly, preaxial						8.81	2.47
Total Limb reduction defects (include unspecified)						3.63	2.47
Transverse						1.50	1.50
Preaxial						0.29	0.21*
Postaxial						0.19	0.04*
Intercalary						0.15	0.03
Mixed						0.63	0.56*
Unspecified						1.31	0.41*
Diaphragmatic hernia						1.55	1.67
Omphalocele						3.53	2.11
Gastroschisis						2.85	3.61
Unspecified Omphalocele/Gastroschisis						1.31	0.00
Prune belly sequence						0.05	0.10
Trisomy 13						0.19	0.21*
Trisomy 18						0.24	0.80
Down syndrome, all ages (include age unknown)						11.85	15.34
<20						6.39	5.47
20-24						6.59	8.07
25-29						7.17	10.96
30-34						16.14	15.29
35-39						41.49	53.07
40-44						138.65	144.86
45+						631.58	170.21*
unknown						---	---

* data include less than 5 years

Russia: MRRCM

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

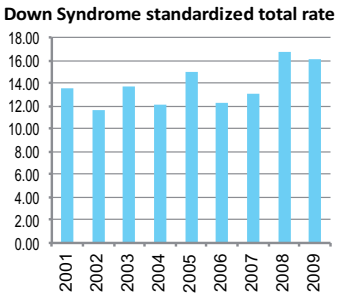


Note: L+S rates, ToP rates

Russia: MRRCM

Note: L+S rates, ToP rates

Russia: MRRCM



Note: L+S rates, ToP rates

Slovak Republic

Slovak Teratologic Information Centre, Slovak Medical University

History:
In Slovakia the collection of reports from delivery units and processing of data performs the National Health Information Centre of SR (NHIC). The obligation of reporting all groups of congenital malformations results from valid legislation norms. 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 Center of Medical Genetics. Research collaboration began from 1995 year, under the responsibility of Dr. Elena Szabova, PhD.

Size and coverage:
The registry covers all births in the area approximately 55.000 births annually according to the Reports of birth defects from delivery units. The detailed information about cases of CM are collected in the Center of Medical Genetics, Bratislava from western regions of Slovakia (cca 15.000 births) by Eva Veghova, MD or under the running research projects at the Slovak Medical University.

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

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

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

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

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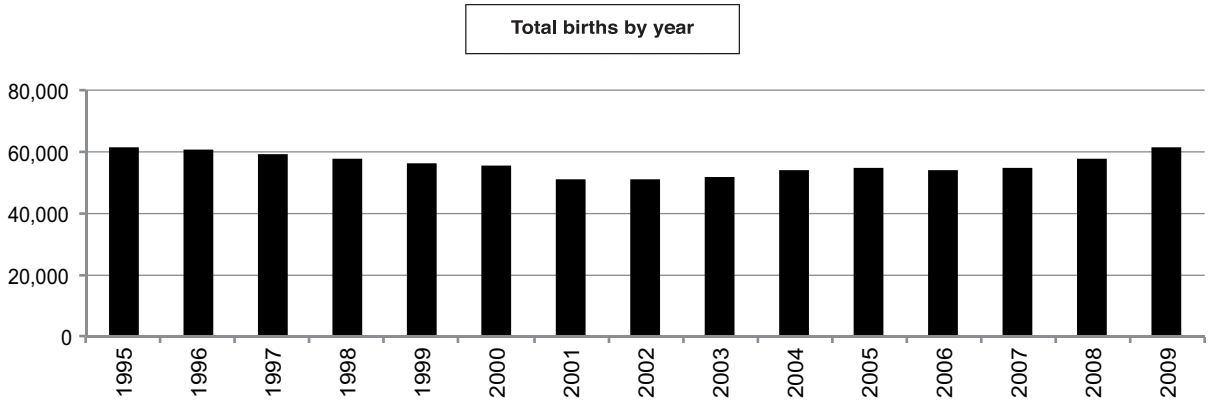
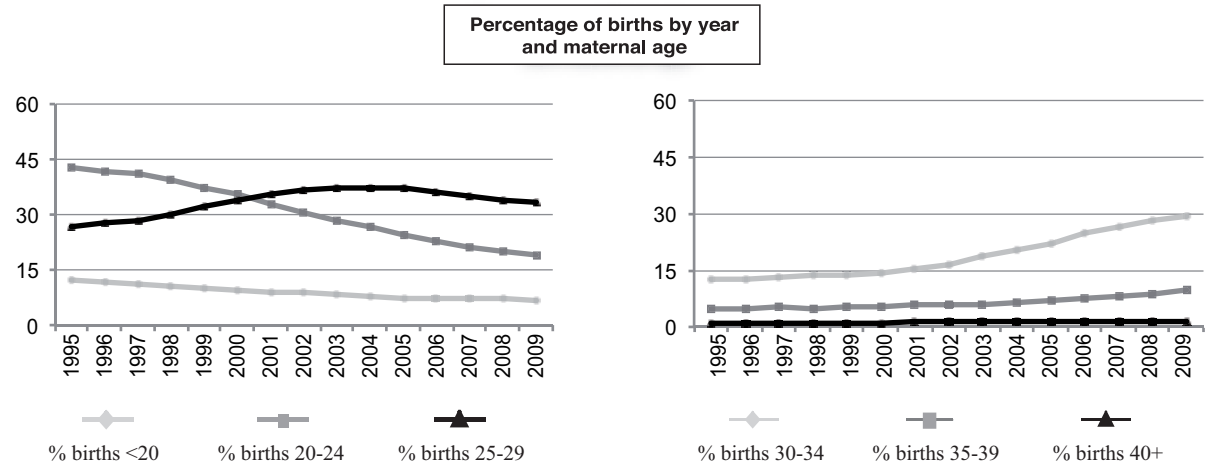
Slovak Republic





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	10	66.7	Cystic kidney	0	0.0
Spina bifida	5	13.5	Limb reduction defects	0	0.0
Encephalocele	5	45.5	Diaphragmatic hernia	1	3.1
Holoprosencephaly	0	0.0	Omphalocele	1	11.1
Hydrocephaly	10	22.7	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	2	50.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	2	20.0
Cleft lip with or without cleft palate	0	0.0	Down syndrome	38	25.0
Renal agenesis	1	1.1			

Total ToPs with births defects = 128 (Ratio ToPs/Births: 0.74 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Slovak Republic, 2009

Live births (LB)	61,217
Stillbirths (SB)	228
Total births	61,445
Number of terminations of pregnancy (ToP) for birth defects	50

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	1	2	0.81
Spina bifida	11	0	3	2.28
Encephalocele	2	0	2	0.65
Microcephaly	5	0	0	0.81
Holoprosencephaly	1	0	0	0.16
Hydrocephaly	14	1	2	2.77
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	0	0.49
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	12	0	0	1.95
Transposition of great vessels	9	0	0	1.46
Tetralogy of Fallot	10	0	0	1.63
Hypoplastic left heart syndrome	10	0	0	1.63
Coarctation of aorta	7	0	0	1.14
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	31	0	0	5.05
Cleft lip with or without cleft palate	60	0	0	9.76
Oesophageal atresia/stenosis with or without fistula	5	0	0	0.81
Small intestine atresia/stenosis	4	0	0	0.65
Anorectal atresia/stenosis	17	0	0	2.77
Undescended testis (36 weeks of gestation or later)	75	1	0	12.37
Hypospadias	97	1	0	15.95
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	0.16
Renal agenesis	34	0	1	5.70
Cystic kidney	5	0	0	0.81
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	16	0	0	2.60
Total Limb reduction defects (include unspecified)	16	0	0	2.60
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	0	1	2.44
Omphalocele	2	0	1	0.49
Gastroschisis	5	0	0	0.81
Unspecified Omphalocele/Gastroschisis	1	0	1	0.33
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	1	0.33
Trisomy 18	3	0	2	0.81
Down syndrome, all ages (include age unknown)	40	0	13	8.63
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported

Slovak Republic, Previous years rates 1995 - 2009

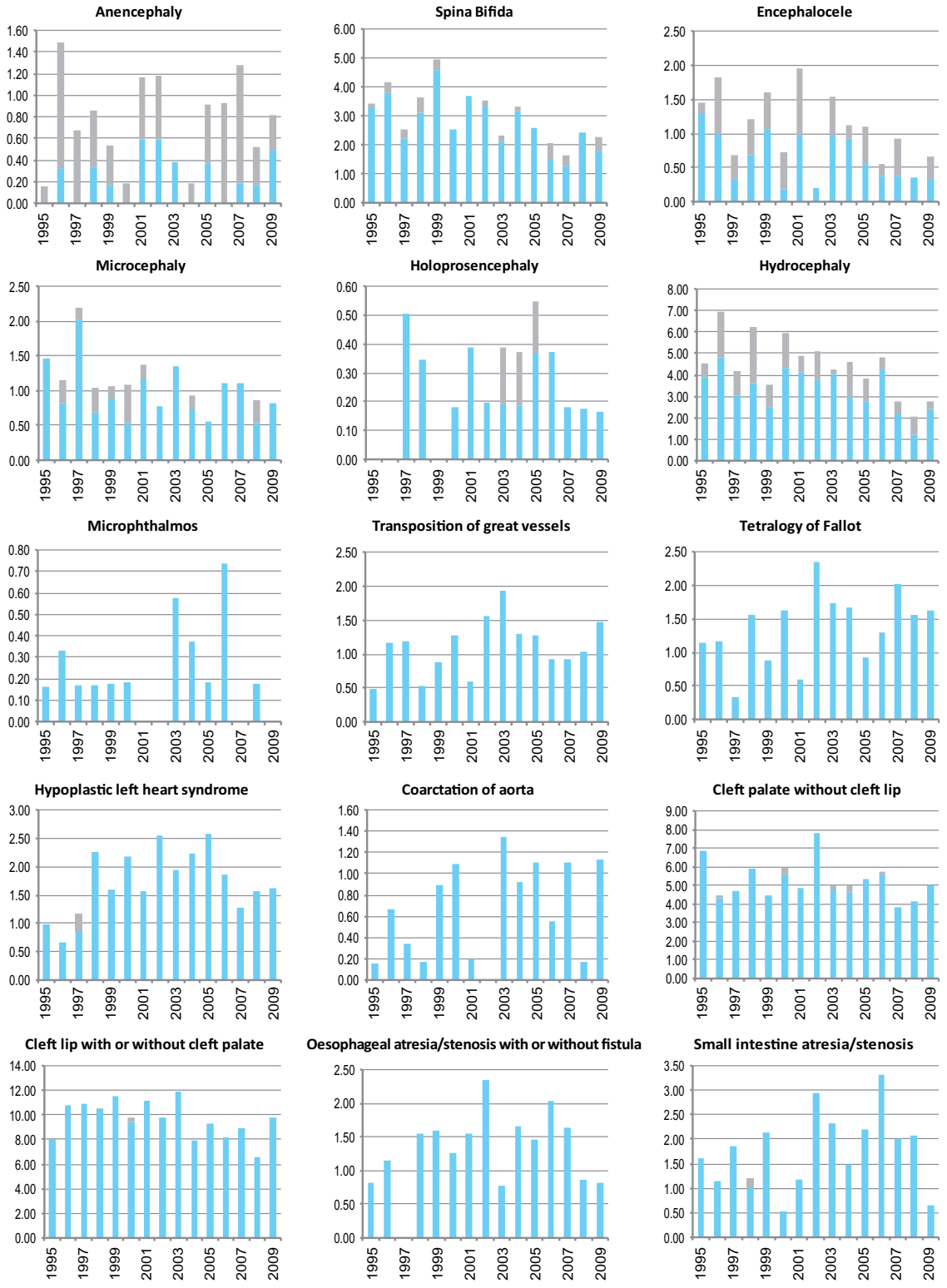
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births					**295,732**	**263,632**	**282,409**
Anencephaly					0.74	0.61	0.89
Spina bifida					3.72	3.07	2.20
Encephalocele					1.35	1.10	0.71
Microcephaly					1.39	1.10	0.89
Holoprosencephaly					0.17	0.30	0.28
Hydrocephaly					5.11	4.97	3.22
Anophthalmos					0.03	0.08	0.04
Microphthalmos					0.20	0.23	0.21
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00
Anotia					0.10	0.15	0.14
Microtia					0.27	0.34	0.14
Unspecified Anotia/Microtia					0.17	0.53	0.85
Transposition of great vessels					0.85	1.33	1.13
Tetralogy of Fallot					1.01	1.59	1.49
Hypoplastic left heart syndrome					1.32	2.09	1.77
Coarctation of aorta					0.44	0.72	0.81
Choanal atresia, bilateral					0.24	0.11	0.25
Cleft palate without cleft lip					5.28	5.73	4.82
Cleft lip with or without cleft palate					10.35	10.09	8.57
Oesophageal atresia/stenosis with or without fistula					1.01	1.52	1.35
Small intestine atresia/stenosis					1.59	1.67	2.02
Anorectal atresia/stenosis					1.56	2.96	2.66
Undescended testis (36 weeks of gestation or later)					6.12	8.34	10.02
Hypospadias					23.26	23.63	17.95
Epispadias					0.17	0.15	0.18
Indeterminate sex					0.51	0.34	0.21
Renal agenesis					2.50	5.46	5.88
Cystic kidney					0.85	1.63	1.10
Bladder exstrophy					0.17	0.19	0.00
Polydactyly, preaxial					1.59	3.57	2.44
Total Limb reduction defects (include unspecified)					3.52	3.64	3.22
Transverse					nr	nr	nr
Preaxial					nr	nr	nr
Postaxial					nr	nr	nr
Intercalary					nr	nr	nr
Mixed					nr	nr	nr
Unspecified					0.03	0.00	0.06*
Diaphragmatic hernia					1.28	1.48	1.81
Omphalocele					0.57	0.68	0.53
Gastroschisis					0.78	1.21	0.85
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.12*
Prune belly sequence					0.00	0.23	0.07
Trisomy 13					0.27	0.34	0.28
Trisomy 18					0.27	0.46	0.60
Down syndrome, all ages (include age unknown)					9.37	10.28	8.89
<20					6.97	4.76	1.84*
20-24					6.50	4.17	3.66*
25-29					6.17	7.14	5.86*
30-34					12.54	11.81	10.09*
35-39					34.56	43.93	27.31*
40-44					71.60	102.73	83.64*
45+					173.91	336.13	125.79*
unknown					---	---	---

nr = not reported
* data include less than 5 years

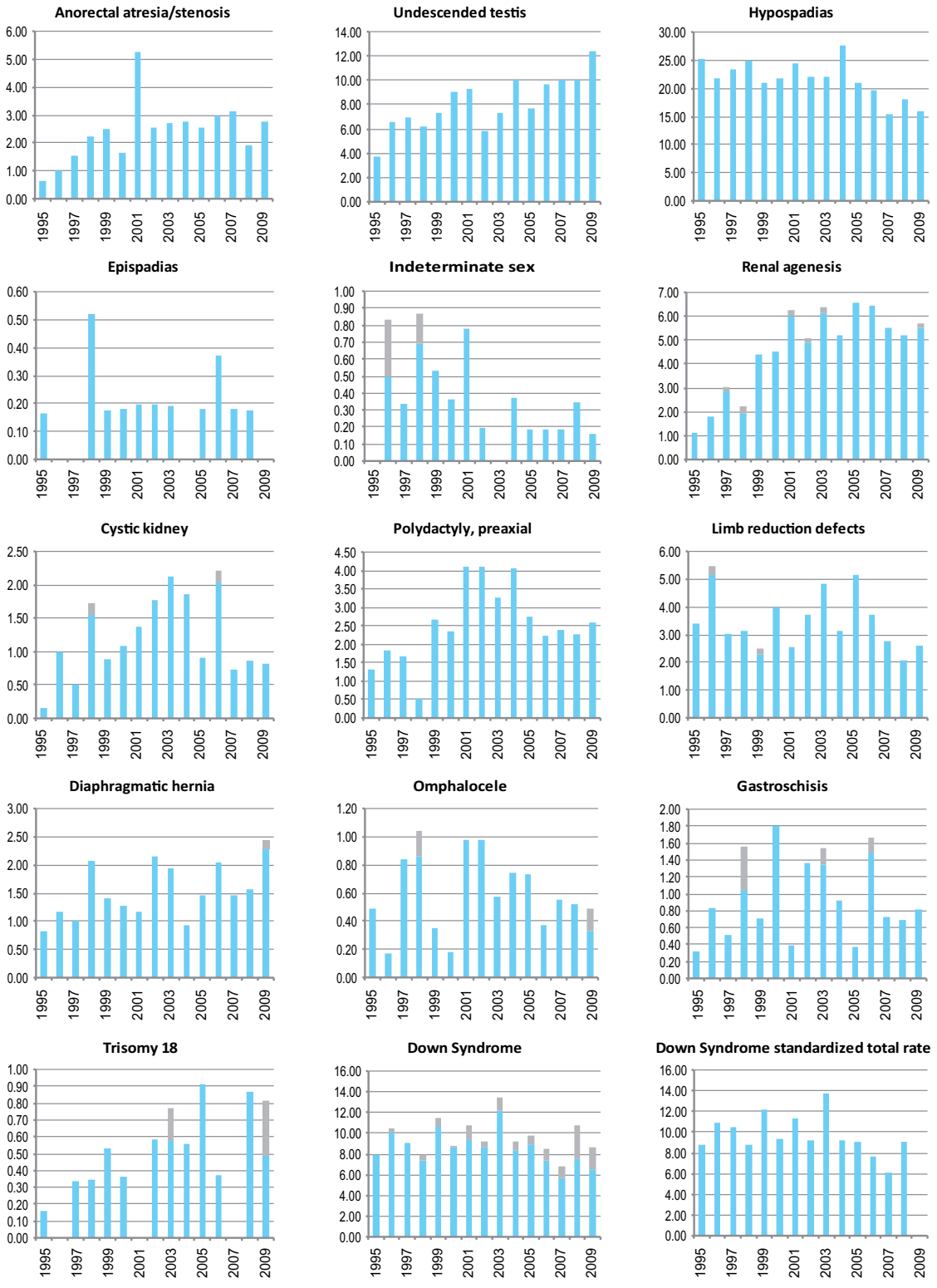
Slovak Republic

Time trends 1995-2009 (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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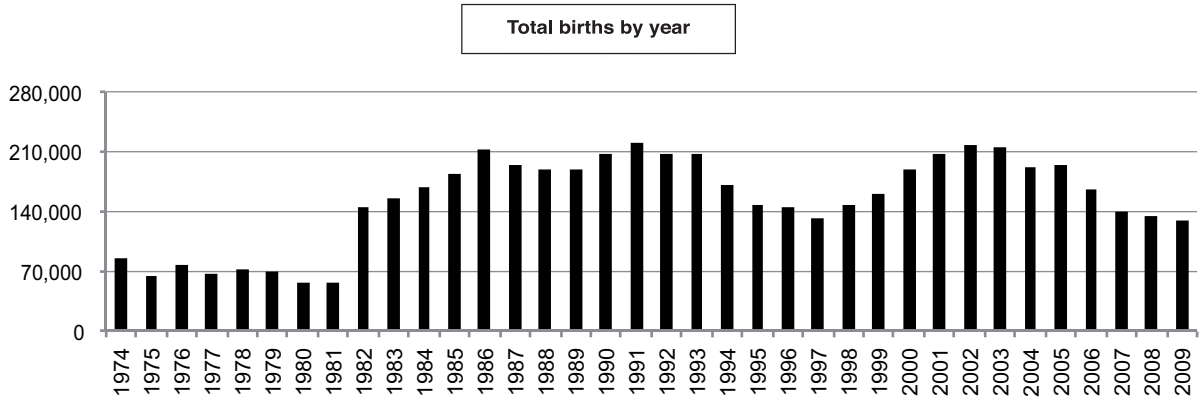
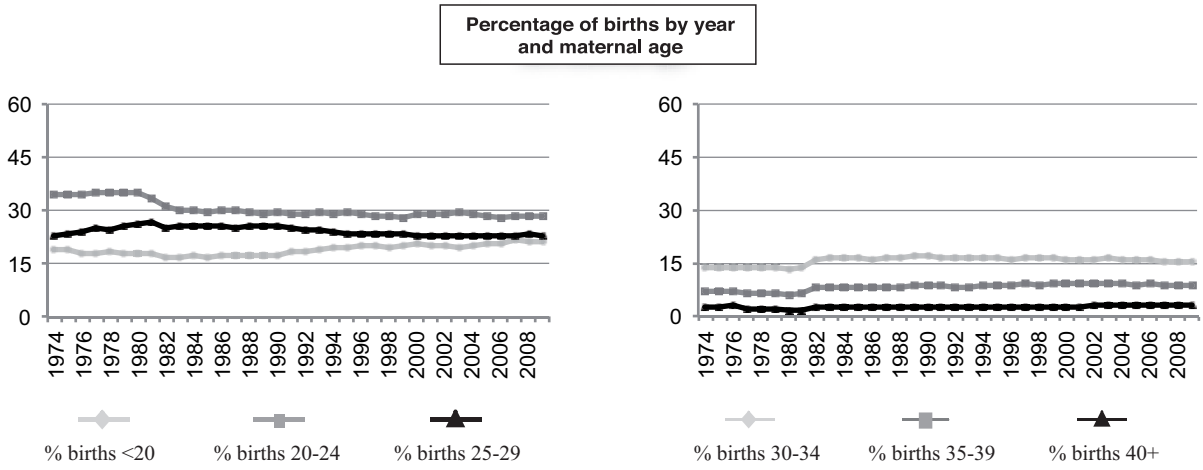
South America: ECLAMC





South America: ECLAMC, 2009

Live births (LB)	126,491
Stillbirths (SB)	1,627
Total births	128,118
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	27	31		4.53
Spina bifida	84	5		6.95
Encephalocele	26	5		2.42
Microcephaly	54	1		4.29
Holoprosencephaly	7	6		1.01
Hydrocephaly	185	8		15.06
Anophthalmos	10	2		0.94
Microphthalmos	12	3		1.17
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	3	0		0.23
Microtia	50	5		4.29
Unspecified Anotia/Microtia	4	1		0.39
Transposition of great vessels	8	0		0.62
Tetralogy of Fallot	11	1		0.94
Hypoplastic left heart syndrome	5	2		0.55
Coarctation of aorta	3	1		0.31
Choanal atresia, bilateral	2	0		0.16
Cleft palate without cleft lip	39	2		3.20
Cleft lip with or without cleft palate	98	9		8.35
Oesophageal atresia/stenosis with or without fistula	38	3		3.20
Small intestine atresia/stenosis	18	1		1.48
Anorectal atresia/stenosis	50	6		4.37
Undescended testis (36 weeks of gestation or later)	112	1		8.82
Hypospadias	86	1		6.79
Epispadias	0	0		0.00
Indeterminate sex	17	4		1.64
Renal agenesis	24	3		2.11
Cystic kidney	62	6		5.31
Bladder exstrophy	3	0		0.23
Polydactyly, preaxial	32	1		2.58
Total Limb reduction defects (include unspecified)	59	6		5.07
Transverse	20	3		1.80
Preaxial	8	1		0.70
Postaxial	1	0		0.08
Intercalary	9	0		0.70
Mixed	20	2		1.72
Unspecified	1	0		0.08
Diaphragmatic hernia	31	2		2.58
Omphalocele	31	11		3.28
Gastroschisis	99	11		8.59
Unspecified Omphalocele/Gastroschisis	0	1		0.08
Prune belly sequence	6	2		0.62
Trisomy 13	2	0		0.16
Trisomy 18	0	0		0.00
Down syndrome, all ages (include age unknown)	154	3		12.25
<20	18	0		6.65
20-24	22	0		6.08
25-29	11	0		3.79
30-34	21	0		10.64
35-39	48	2		45.10
40-44	32	1		95.46
45+	1	0		41.67
unknown	1	0		---

nr = not reported

South America: ECLAMC, Previous years rates 1974 - 2009

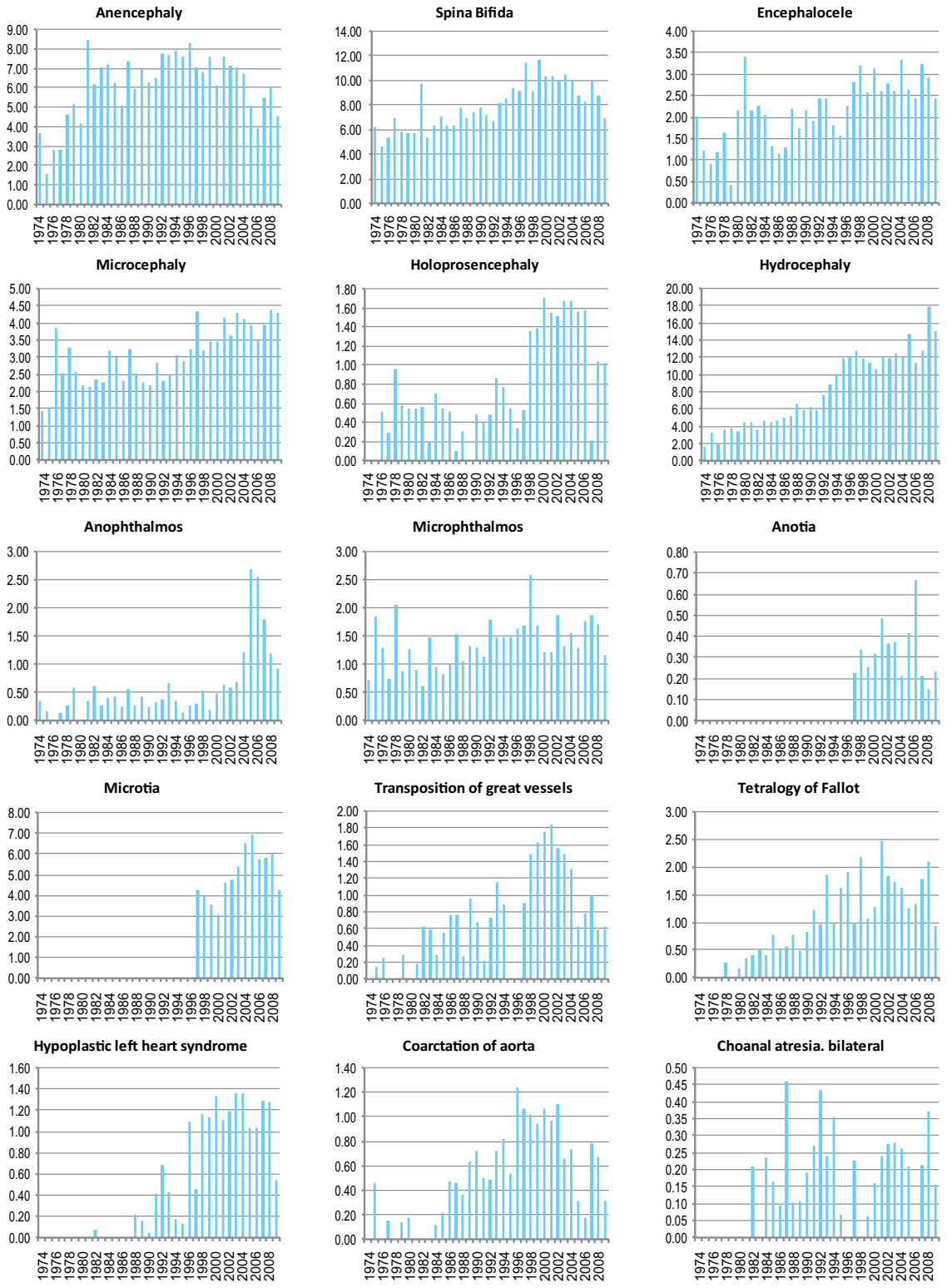
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**438,055**	**579,119**	**968,001**	**1,012,539**	**731,513**	**1,018,471**	**759,401**
Anencephaly	3.47	6.73	6.28	7.18	7.49	6.93	4.96
Spina bifida	5.82	6.54	6.97	7.62	10.14	10.22	8.55
Encephalocele	1.26	2.28	1.53	2.16	2.47	2.89	2.71
Microcephaly	2.53	2.54	2.67	2.57	3.40	3.94	3.99
Holoprosencephaly	0.39	0.50	0.30	0.59	0.85	1.62	1.13
Hydrocephaly	2.88	4.30	5.50	7.68	11.93	11.84	14.26
Anophthalmos	0.25	0.38	0.38	0.40	0.29	0.72	1.94
Microphthalmos	1.23	1.04	1.15	1.43	1.82	1.44	1.55
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	0.27*	0.35	0.36
Microtia	nr	nr	nr	nr	3.91*	4.88	5.87
Unspecified Anotia/Microtia	nr	nr	nr	nr	0.09*	0.10	0.16
Transposition of great vessels	0.11	0.41	0.66	0.72	1.03	1.59	0.72
Tetralogy of Fallot	0.05	0.41	0.62	1.19	1.56	1.80	1.46
Hypoplastic left heart syndrome	0.00	0.02	0.07	0.36	0.81	1.27	1.04
Coarctation of aorta	0.11	0.05	0.43	0.64	0.96	0.90	0.43
Choanal atresia, bilateral	0.00	0.12	0.19	0.30	0.07	0.25	0.18
Cleft palate without cleft lip	3.20	3.35	3.31	3.87	3.73	5.03	4.36
Cleft lip with or without cleft palate	11.07	10.53	10.83	10.46	12.59	13.46	12.54
Oesophageal atresia/stenosis with or without fistula	2.01	2.68	2.58	2.83	3.40	3.67	3.44
Small intestine atresia/stenosis	0.48	1.64	1.44	1.82	2.01	3.06	2.94
Anorectal atresia/stenosis	2.76	3.82	3.64	4.46	4.85	5.70	5.25
Undescended testis (36 weeks of gestation or later)	1.58	3.35	4.58	4.80	5.21	6.74	9.47
Hypospadias	3.47	4.71	4.00	4.36	5.10	5.04	6.89
Epispadias	0.14	0.38	0.28	0.36	0.12	0.23	0.14
Indeterminate sex	1.00	2.33	1.90	1.88	1.72	2.29	2.54
Renal agenesis	0.43	0.66	0.85	1.61	2.24	2.50	2.54
Cystic kidney	0.55	1.11	1.47	2.06	3.70	4.28	4.04
Bladder exstrophy	0.14	0.21	0.28	0.25	0.33	0.39	0.22
Polydactyly, preaxial	2.97	2.28	2.52	2.64	2.95	3.92	3.69
Total Limb reduction defects (include unspecified)	4.09	5.49	4.83	5.52	6.14	6.77	7.85
Transverse	2.15	2.61	2.70	2.73	2.95	3.63	2.45
Preaxial	0.62	1.11	0.99	1.11	1.57	1.40	1.19
Postaxial	0.27	0.50	0.26	0.47	0.40	0.41	0.46
Intercalary	0.48	0.59	0.34	0.49	0.56	0.47	0.87
Mixed	0.48	0.60	0.42	0.58	0.55	0.63	2.38
Unspecified	0.09	0.09	0.12	0.14	0.11	0.22	0.50
Diaphragmatic hernia	0.73	1.31	1.73	2.13	3.43	3.89	3.49
Omphalocele	1.10	1.93	2.32	2.51	3.17	3.40	4.21
Gastroschisis	0.09	0.40	0.65	1.18	2.64	3.26	7.33
Unspecified Omphalocele/Gastroschisis	0.37	0.36	0.40	0.47	1.01	1.35	0.55
Prune belly sequence	0.02	0.54	0.74	0.74	1.18	1.03	0.75
Trisomy 13	0.18	0.50	0.43	0.55	0.85	0.89	0.53
Trisomy 18	0.23	0.71	0.99	0.98	1.78	2.02	1.37
Down syndrome, all ages (include age unknown)	14.63	14.78	14.94	15.84	18.00	19.75	17.51
<20	7.68	7.10	6.76	6.83	8.37	6.85	9.22
20-24	7.09	7.33	6.30	7.97	8.69	10.15	7.93
25-29	7.60	8.30	6.89	8.72	9.40	10.33	8.64
30-34	13.66	15.81	15.47	15.48	16.87	16.86	16.60
35-39	56.45	44.24	44.49	47.05	50.39	57.76	49.57
40-44	161.18	141.15	152.52	148.49	179.36	177.78	151.17
45+	269.28	283.57	270.52	244.78	361.34	374.62	329.90
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

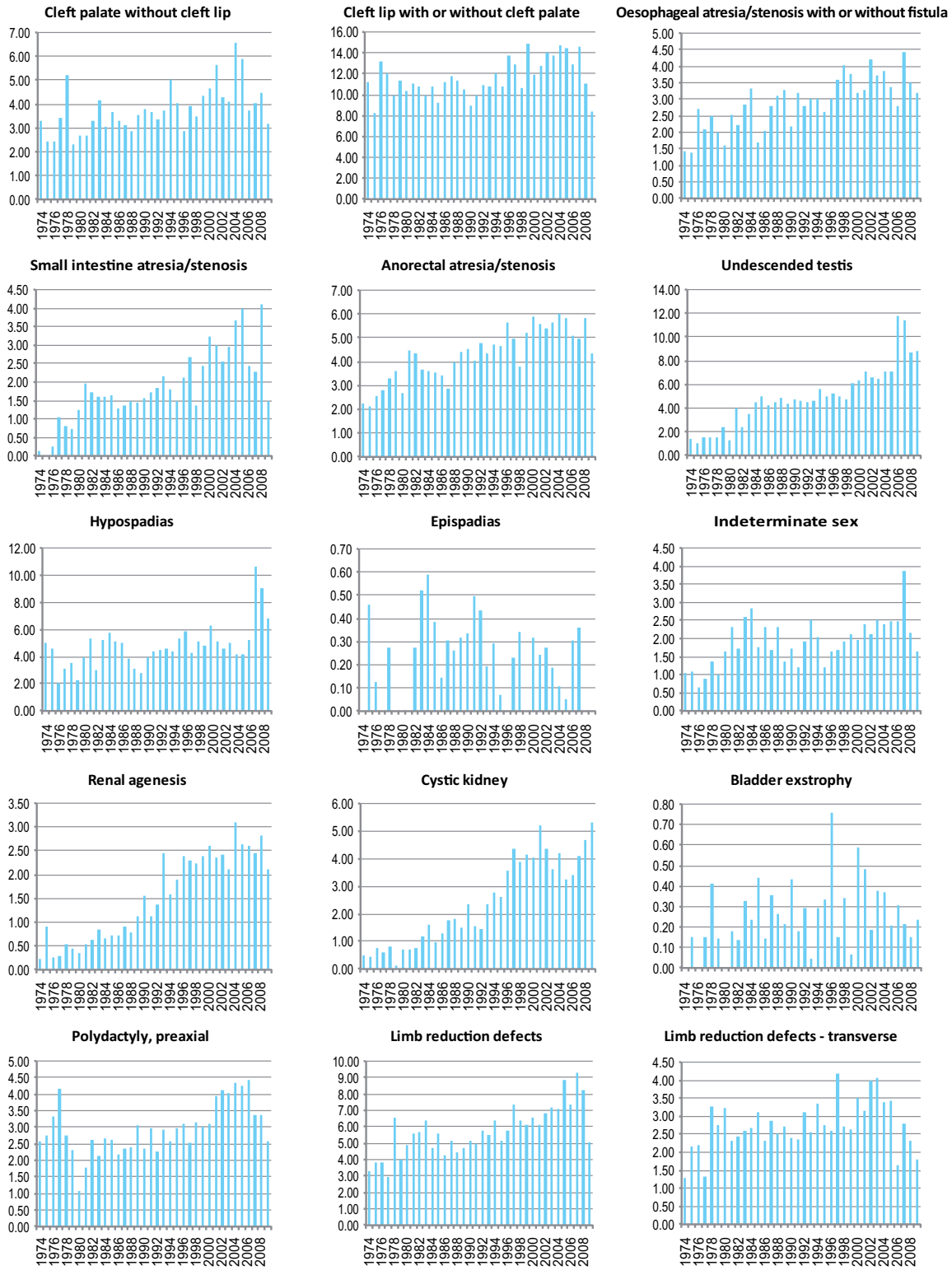
South America: ECLAMC

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



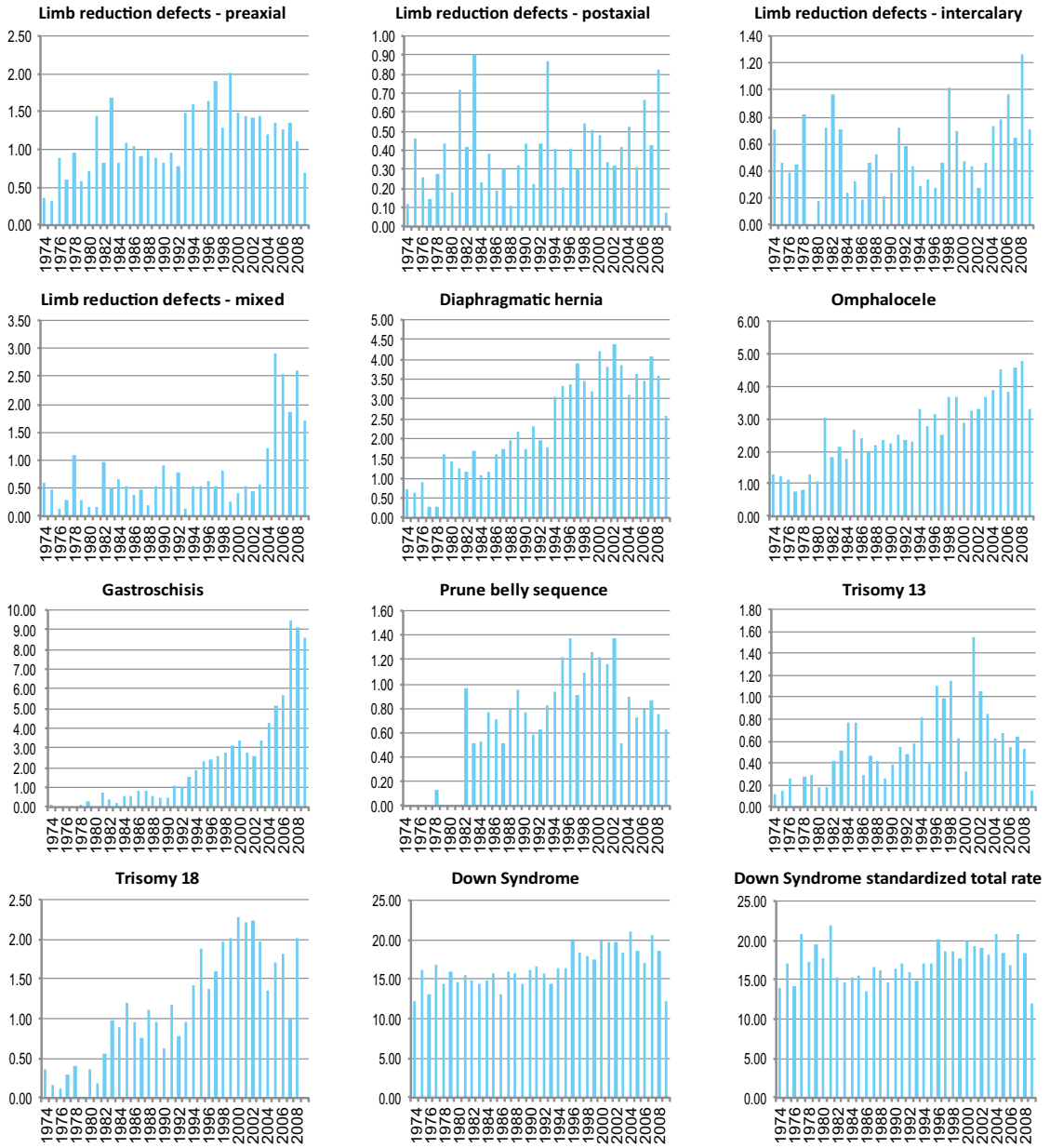
Note: L+S rates

South America: ECLAMC



Note: L+S rates

South America: ECLAMC



Note: L+S rates

Spain: ECEMC
Spanish Collaborative Study of Congenital Malformations

History:
The programme was created in 1976 by Prof. Dr. María Luisa Martínez-Frías, as a hospital-based case-control study and surveillance system. ECEMC joined ICBDSR in 1979. It is also a member of EUROCAT contributing with data since 1980. In January 2002 the ECEMC Programme became integrated into the CIAC (Research Center on Congenital Anomalies), of the Instituto de Salud Carlos III (ISCIII), now dependent from the Ministerio de Economía y Competitividad, 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, the two TIS and CIAC are directed by Prof. Martínez-Frías.

Size and coverage:
Data are obtained from about 70 hospitals distributed all over Spain. The annual number of births is about 100,000, representing more than 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.

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 300 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 analysis when needed (which are performed at the central group of the ECEMC), and other complementary studies are available. Biological samples are also stored in the ECEMC registry for those cases and controls for which the collaborating physicians send them, with the informed consent of the parents.

Exposure information:
The mother of each reported infant (case or control) is interviewed within the first three days after delivery to obtain data on several exposures (parental occupation, maternal acute or chronic diseases, drug usage, illicit drugs, alcohol and tobacco maternal consumption, exposure to other chemical or physical factors), apart from the other data gathered (family history, obstetrical and demographic data, paternal exposures among others). It is important to note that when the pediatricians 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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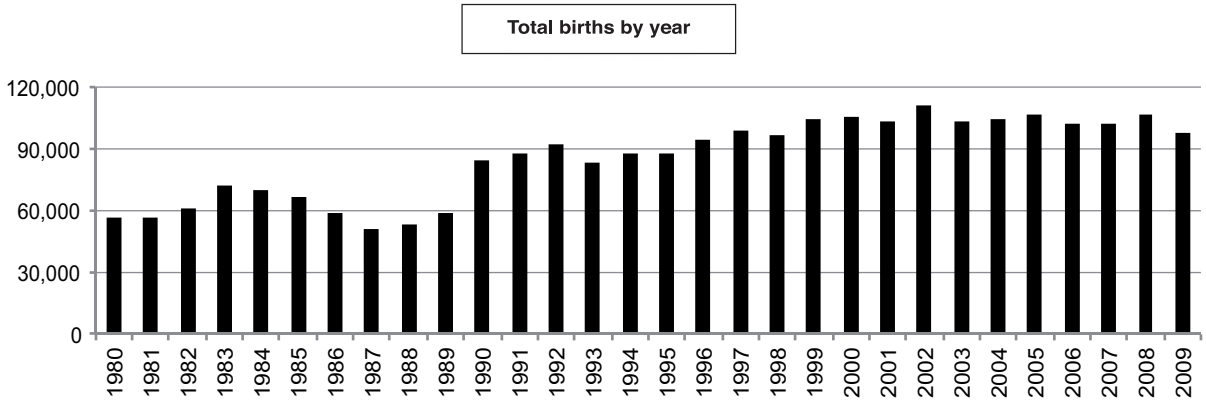
Lecturer of the Department of Epidemiology & Population Health (Medical Statistics Unit)
London School of Hygiene & Tropical Medicine

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
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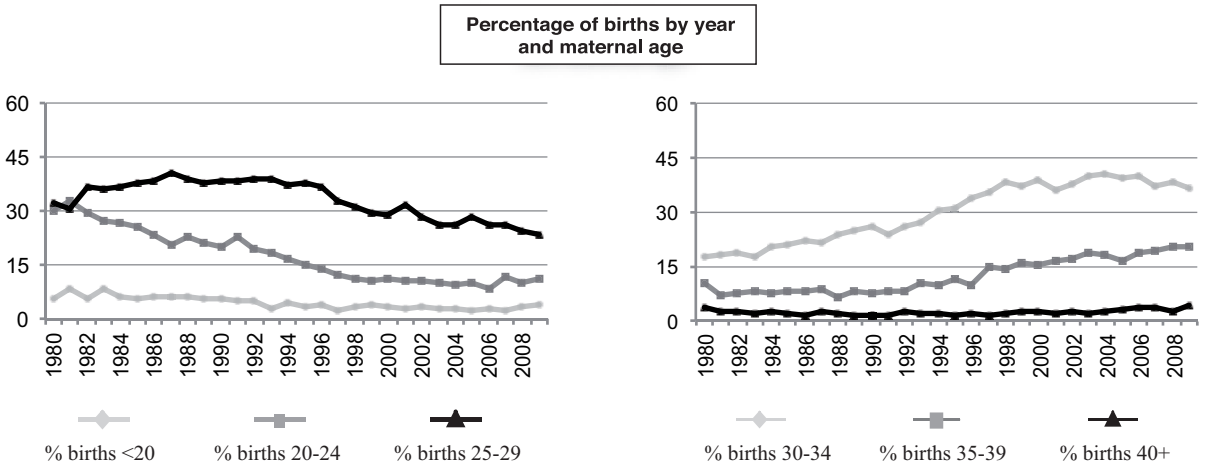
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009


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
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Spain: ECEMC, 2009

Live births (LB)	97,725
Stillbirths (SB)	345
Total births	98,070
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	0	nr	0.00
Spina bifida	5	0	nr	0.51
Encephalocele	0	1	nr	0.10
Microcephaly	8	0	nr	0.82
Holoprosencephaly	3	1	nr	0.41
Hydrocephaly	14	0	nr	1.43
Anophthalmos	2	0	nr	0.20
Microphthalmos	9	0	nr	0.92
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	22	1	nr	2.35
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	10	1	nr	1.12
Tetralogy of Fallot	7	0	nr	0.71
Hypoplastic left heart syndrome	1	0	nr	0.10
Coarctation of aorta	2	1	nr	0.31
Choanal atresia, bilateral	3	0	nr	0.31
Cleft palate without cleft lip	26	0	nr	2.65
Cleft lip with or without cleft palate	22	1	nr	2.35
Oesophageal atresia/stenosis with or without fistula	12	1	nr	1.33
Small intestine atresia/stenosis	4	0	nr	0.41
Anorectal atresia/stenosis	7	1	nr	0.82
Undescended testis (36 weeks of gestation or later)	21	1	nr	2.24
Hypospadias	14	0	nr	1.43
Epispadias	2	0	nr	0.20
Indeterminate sex	8	0	nr	0.82
Renal agenesis	0	0	nr	0.00
Cystic kidney	11	1	nr	1.22
Bladder exstrophy	1	0	nr	0.10
Polydactyly, preaxial	21	0	nr	2.14
Total Limb reduction defects (include unspecified)	37	3	nr	4.08
Transverse	16	1	nr	1.73
Preaxial	5	1	nr	0.61
Postaxial	0	0	nr	0.00
Intercalary	1	0	nr	0.10
Mixed	9	0	nr	0.92
Unspecified	6	1	nr	0.71
Diaphragmatic hernia	7	1	nr	0.82
Omphalocele	5	0	nr	0.51
Gastroschisis	4	3	nr	0.71
Unspecified Omphalocele/Gastroschisis	1	0	nr	0.10
Prune belly sequence	2	0	nr	0.20
Trisomy 13	0	1	nr	0.10
Trisomy 18	3	2	nr	0.51
Down syndrome, all ages (include age unknown)	68	3	nr	7.24
<20	0	0	nr	0.00
20-24	2	1	nr	2.66
25-29	7	0	nr	3.03
30-34	21	0	nr	5.87
35-39	24	1	nr	12.51
40-44	9	1	nr	27.96
45+	5	0	nr	111.86
unknown	0	0	nr	---

nr = not reported

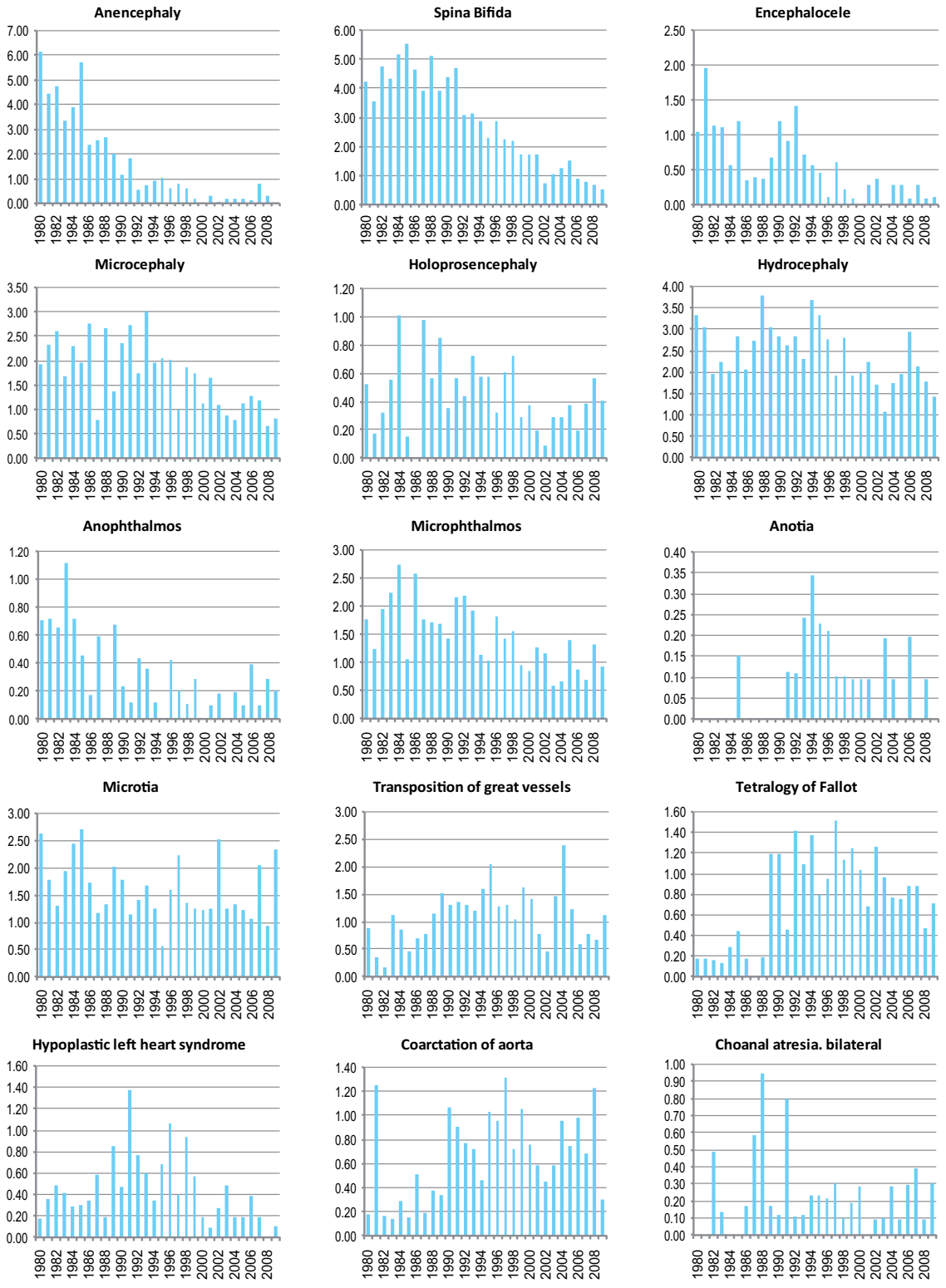
Spain: ECEMC, Previous years rates 1980 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births		**315,670**	**287,748**	**433,858**	**481,187**	**527,288**	**515,449**
Anencephaly		4.44	3.16	1.04	0.64	0.15	0.27
Spina bifida		4.44	4.66	3.62	2.24	1.29	0.87
Encephalocele		1.14	0.63	0.97	0.29	0.19	0.17
Microcephaly		2.15	1.91	2.35	1.72	1.10	1.01
Holoprosencephaly		0.54	0.49	0.53	0.50	0.25	0.39
Hydrocephaly		2.47	2.88	2.86	2.51	1.74	2.06
Anophthalmos		0.79	0.38	0.25	0.21	0.09	0.21
Microphthalmos		2.03	1.74	1.77	1.35	0.91	1.05
Unspecified Anophthalmos/Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.00	0.03	0.16	0.15	0.09	0.06
Microtia		2.03	1.84	1.45	1.41	1.54	1.51
Unspecified Anotia/Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		0.70	0.90	1.36	1.45	1.29	0.87
Tetralogy of Fallot		0.19	0.42	1.11	1.14	0.95	0.74
Hypoplastic left heart syndrome		0.35	0.45	0.71	0.73	0.25	0.17
Coarctation of aorta		0.38	0.31	0.78	1.02	0.66	0.80
Choanal atresia, bilateral		0.13	0.35	0.28	0.21	0.15	0.23
Cleft palate without cleft lip		5.13	3.96	5.32	3.99	3.94	3.43
Cleft lip with or without cleft palate		5.89	5.14	5.90	4.49	3.74	3.12
Oesophageal atresia/stenosis with or without fistula		2.31	1.60	2.35	1.60	1.97	1.63
Small intestine atresia/stenosis		0.60	0.42	0.55	0.37	0.63	0.54
Anorectal atresia/stenosis		2.50	2.36	2.07	2.18	1.95	1.67
Undescended testis (36 weeks of gestation or later)		1.81	2.50	2.67	2.91	2.39	2.10
Hypospadias		2.79	2.19	2.07	1.66	2.28	1.44
Epispadias		0.22	0.14	0.25	0.06	0.08	0.10
Indeterminate sex		1.01	0.94	0.88	0.60	0.55	0.49
Renal agenesis		0.60	0.94	0.65	0.50	0.06	0.10
Cystic kidney		1.17	1.46	1.73	1.79	1.40	1.63
Bladder exstrophy		0.22	0.42	0.21	0.27	0.21	0.17
Polydactyly, preaxial		2.38	2.50	3.43	2.58	1.84	2.37
Total Limb reduction defects (include unspecified)		7.41	6.32	7.05	5.84	4.67	4.25
Transverse		3.14	2.81	2.47	2.41	1.86	1.71
Preaxial		1.20	1.04	0.92	0.73	0.59	0.60
Postaxial		0.13	0.17	0.18	0.25	0.11	0.10
Intercalary		0.57	0.24	0.65	0.15	0.34	0.17
Mixed		1.17	0.87	1.24	1.10	0.89	0.91
Unspecified		1.20	1.18	1.59	1.21	0.68	0.49
Diaphragmatic hernia		2.76	2.12	2.24	1.54	0.63	1.13
Omphalocele		1.81	1.32	1.11	0.91	0.53	0.56
Gastroschisis		0.60	0.38	0.35	0.46	0.36	0.68
Unspecified Omphalocele/Gastroschisis		0.32	0.38	0.21	0.06	0.02	0.02
Prune belly sequence		0.57	0.52	0.55	0.31	0.15	0.23
Trisomy 13		0.38	0.45	0.46	0.52	0.34	0.23
Trisomy 18		0.89	0.97	1.08	0.69	0.64	0.66
Down syndrome, all ages (include age unknown)		14.41	15.22	12.70	10.85	7.97	7.10
<20		7.35	8.07	8.57	1.81	1.79	5.59
20-24		6.98	6.37	4.50	5.08	4.90	4.86
25-29		6.10	8.18	7.74	5.78	5.00	3.47
30-34		9.77	15.09	14.26	10.92	6.98	5.53
35-39		46.67	41.61	35.92	23.78	12.68	11.71
40-44		147.44	186.36	64.92	51.95	45.00	28.29
45+		233.13	141.70	248.45	531.91	42.64	89.80
unknown		---	---	---	---	---	---

Spain: ECEMC

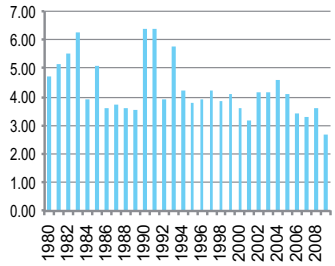
Time trends 1980-2009 (Birth prevalence rates per 10,000)



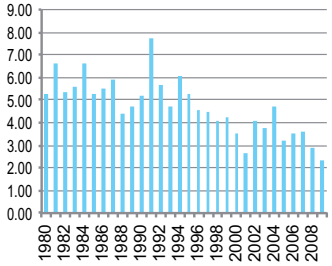
Note: L+S rates

Spain: ECEMC

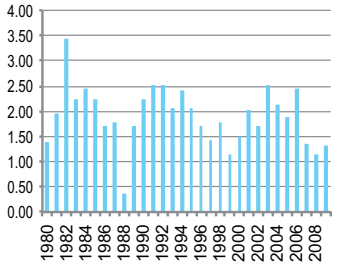
Cleft palate without cleft lip



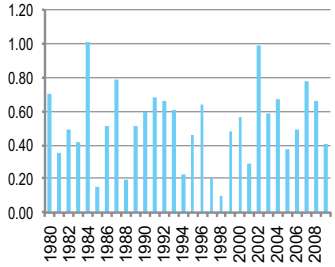
Cleft lip with or without cleft palate



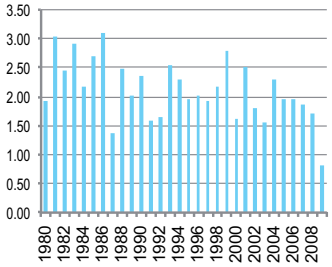
Oesophageal atresia/stenosis with or without fistula



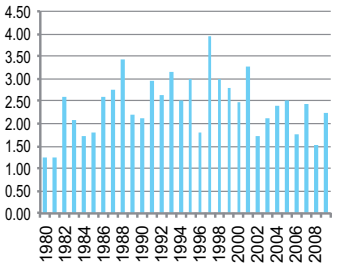
Small intestine atresia/stenosis



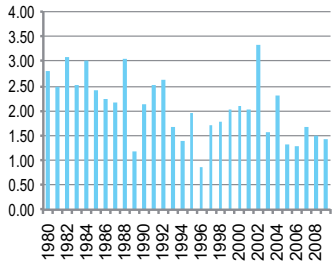
Anorectal atresia/stenosis



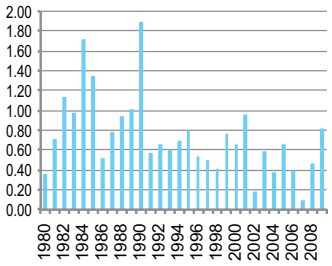
Undescended testis



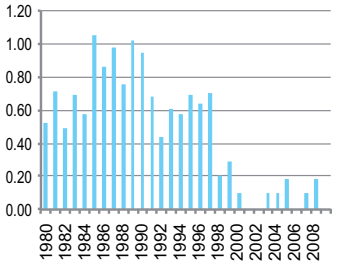
Hypospadias



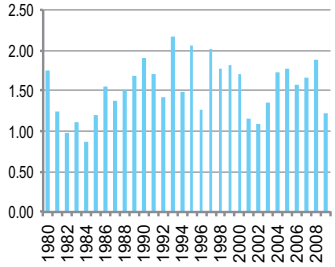
Indeterminate sex



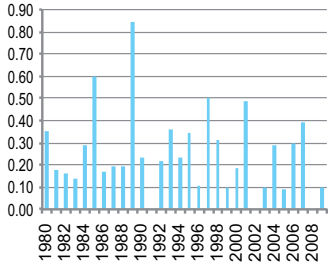
Renal agenesis



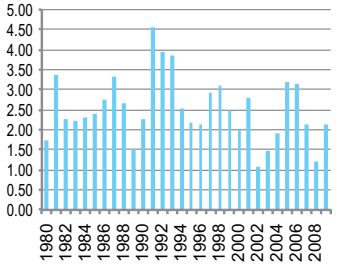
Cystic kidney



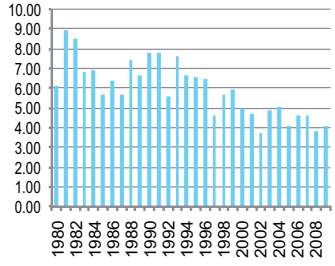
Bladder exstrophy



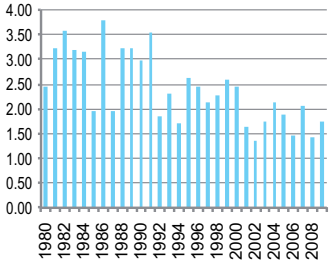
Polydactyly, preaxial



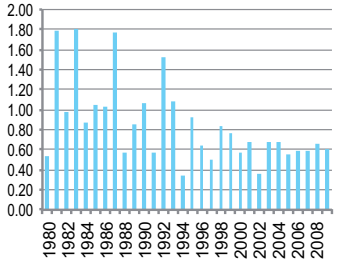
Limb reduction defects



Limb reduction defects - transverse



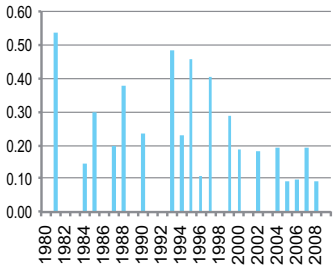
Limb reduction defects - preaxial



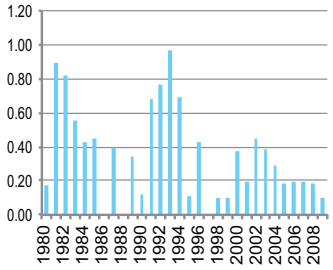
Note: L+S rates

Spain: ECEMC

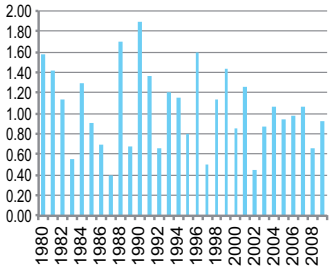
Limb reduction defects - postaxial



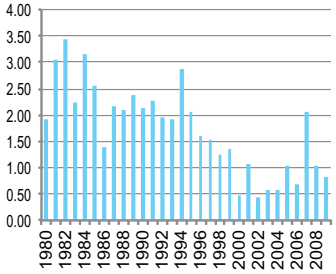
Limb reduction defects - intercalary



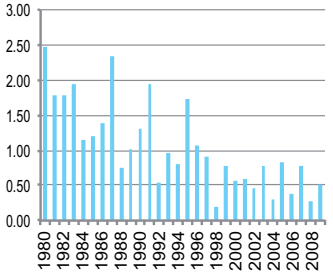
Limb reduction defects - mixed



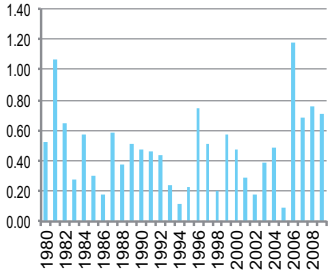
Diaphragmatic hernia



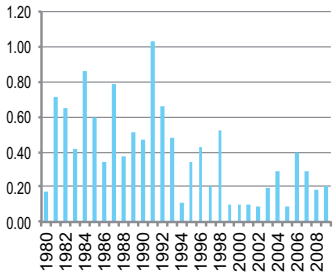
Omphalocele



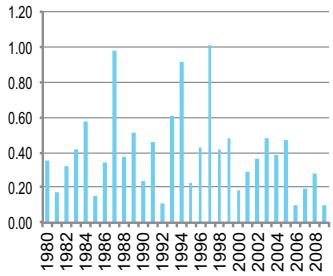
Gastroschisis



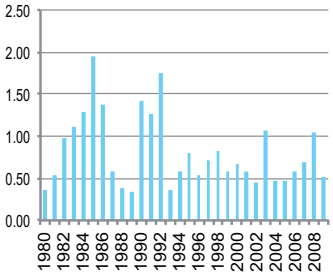
Prune belly sequence



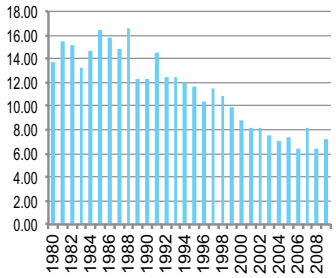
Trisomy 13



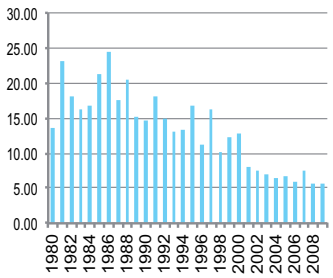
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Sweden

The Swedish Registry of Congenital Malformations and the Medical Birth Registry

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

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

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

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

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

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

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Fax: 46-18-554025
E-Mail: goran.anneren@genpat.uu.se

Karin Källén Ph.D., National Board of Health and Social Welfare, S-106 30 Stockholm, Sweden
Phone: 46-46-2227538
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Karin Gottvall, Ph.D., National Board of Health and Social Welfare, S-106 30 Stockholm, Sweden
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Fax: 46-8-752473176
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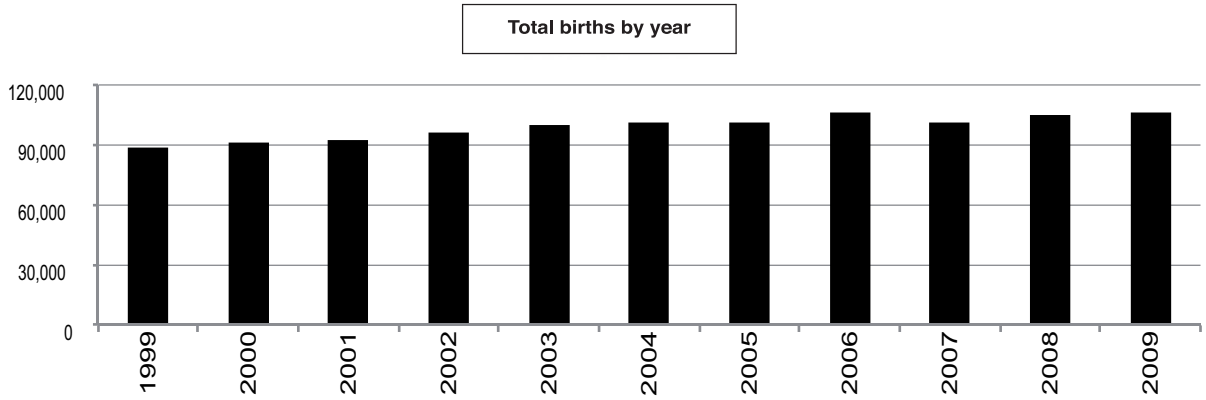
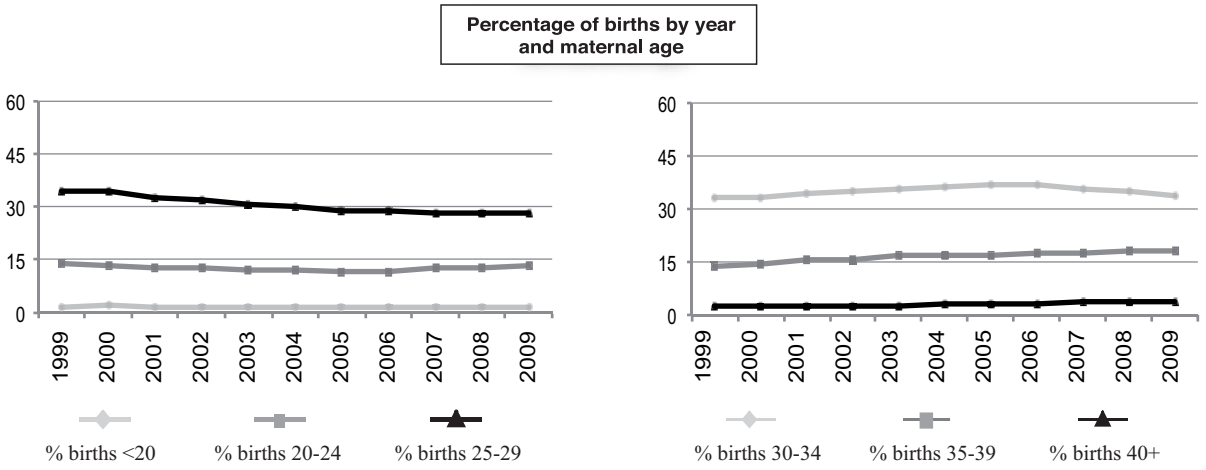
Sweden





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	93	92.1	Cystic kidney	39	37.9
Spina bifida	84	59.6	Limb reduction defects	29	18.7
Encephalocele	31	77.5	Diaphragmatic hernia	43	43.4
Holoprosencephaly	14	66.7	Omphalocele	48	72.7
Hydrocephaly	66	65.3	Gastroschisis	13	25.5
Hypoplastic left heart syndrome	46	59.7	Trisomy 13	86	78.9
Cleft palate without cleft lip	7	4.1	Trisomy 18	195	79.3
Cleft lip with or without cleft palate	8	4.1	Down syndrome	534	57.3
Renal agenesis	34	50.7			

Total ToPs with births defects = 1,647 (Ratio ToPs/Births: 5.25 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Sweden, 2009

Live births (LB)	106,320
Stillbirths (SB)	435
Total births	106,755
Number of terminations of pregnancy (ToP) for birth defects	582

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	1	28	3.00
Spina bifida	18	0	22	3.75
Encephalocele	4	0	7	1.03
Microcephaly	3	0	3	0.56
Holoprosencephaly	1	0	6	0.66
Hydrocephaly	13	0	21	3.18
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	1	0.28
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	4	0	0	0.37
Microtia	3	0	0	0.28
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	18	0	3	1.97
Tetralogy of Fallot	20	0	2	2.06
Hypoplastic left heart syndrome	9	0	13	2.06
Coarctation of aorta	38	0	5	4.03
Choanal atresia, bilateral	6	0	0	0.56
Cleft palate without cleft lip	50	0	3	4.96
Cleft lip with or without cleft palate	91	0	6	9.09
Oesophageal atresia/stenosis with or without fistula	28	0	2	2.81
Small intestine atresia/stenosis	20	0	1	1.97
Anorectal atresia/stenosis	30	0	6	3.37
Undescended testis (36 weeks of gestation or later)	5	0	0	0.47
Hypospadias	265	0	1	24.92
Epispadias	4	0	0	0.37
Indeterminate sex	1	0	0	0.09
Renal agenesis	12	0	4	1.50
Cystic kidney	20	0	16	3.37
Bladder exstrophy	2	0	0	0.19
Polydactyly, preaxial	23	0	1	2.25
Total Limb reduction defects (include unspecified)	47	0	12	5.53
Transverse	29	0	9	3.56
Preaxial	3	0	1	0.37
Postaxial	3	0	0	0.28
Intercalary	4	0	0	0.37
Mixed	9	0	2	1.03
Unspecified	0	0	0	0.00
Diaphragmatic hernia	19	0	9	2.62
Omphalocele	7	0	22	2.72
Gastroschisis	11	1	5	1.59
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.09
Trisomy 13	7	0	37	4.12
Trisomy 18	12	1	68	7.59
Down syndrome, all ages (include age unknown)	142	1	207	32.79
<20	1	0	0	5.64
20-24	3	1	1	3.53
25-29	16	0	8	7.86
30-34	37	0	28	17.83
35-39	39	0	77	58.99
40-44	31	0	82	284.56
45+	12	0	10	1062.80
unknown	3	0	1	---

nr = not reported

Sweden, Previous years rates 1999 - 2009

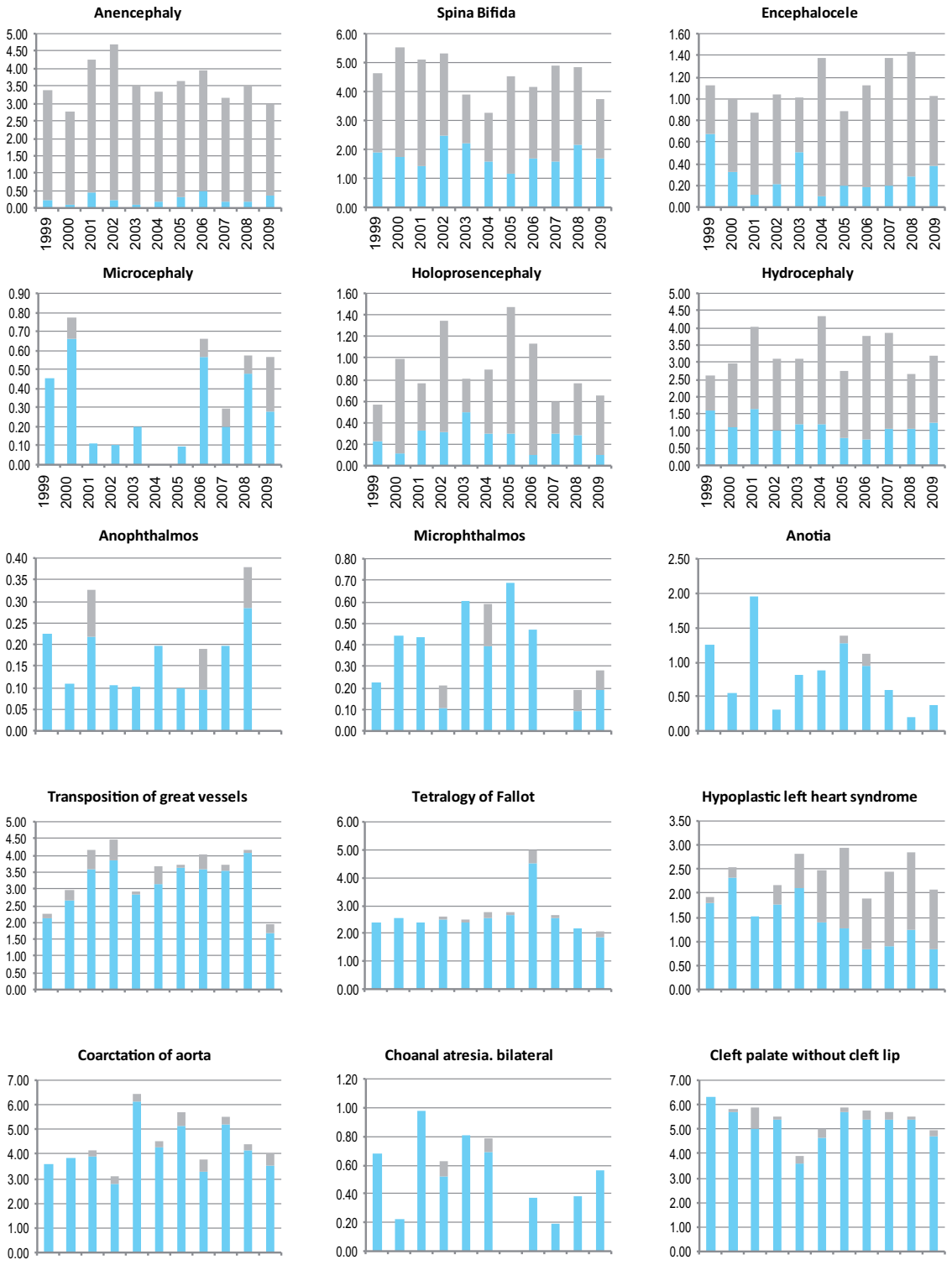
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999*	2000-2004	2005-2009
Total births					**88,512**	**479,555**	**521,583**
Anencephaly					3.39	3.71	3.45
Spina bifida					4.63	4.59	4.43
Encephalocele					1.13	1.06	1.17
Microcephaly					0.45	0.23	0.44
Holoprosencephaly					0.56	0.96	0.92
Hydrocephaly					2.60	3.52	3.24
Anophthalmos					0.23	0.17	0.17
Microphthalmos					0.23	0.46	0.33
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.10
Anotia					1.24	0.90	0.73
Microtia					0.00	0.10	0.27
Unspecified Anotia/Microtia					0.00	0.00	0.06
Transposition of great vessels					2.26	3.63	3.53
Tetralogy of Fallot					2.37	2.56	2.93
Hypoplastic left heart syndrome					1.92	2.31	2.43
Coarctation of aorta					3.62	4.44	4.66
Choanal atresia, bilateral					0.68	0.69	0.31
Cleft palate without cleft lip					6.33	5.21	5.56
Cleft lip with or without cleft palate					11.64	9.78	8.01
Oesophageal atresia/stenosis with or without fistula					1.69	2.63	2.47
Small intestine atresia/stenosis					2.49	2.46	2.19
Anorectal atresia/stenosis					3.50	3.04	2.80
Undescended testis (36 weeks of gestation or later)					nr	nr	0.22*
Hypospadias					20.79	20.35	22.41
Epispadias					0.11	0.21	0.21
Indeterminate sex					0.11	0.27	0.19
Renal agenesis					2.49	1.67	1.67
Cystic kidney					2.94	3.11	3.66
Bladder exstrophy					0.34	0.25	0.27
Polydactyly, preaxial					3.62	4.69	3.20
Total Limb reduction defects (include unspecified)					4.63	5.17	4.83
Transverse					2.71	3.86	2.99
Preaxial					0.23	0.25	0.54
Postaxial					0.11	0.19	0.15
Intercalary					0.11	0.23	0.25
Mixed					1.47	0.65	0.58
Unspecified					0.00	0.00	1.10
Diaphragmatic hernia					3.05	2.69	3.14
Omphalocele					2.26	2.61	2.45
Gastroschisis					2.37	1.77	1.69
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00
Prune belly sequence					0.11	0.10	0.21
Trisomy 13					2.03	2.31	3.34
Trisomy 18					5.87	6.05	8.24
Down syndrome, all ages (include age unknown)					22.48	24.48	28.91
<20					5.97	9.62	10.25
20-24					7.22	9.32	7.06
25-29					6.26	9.12	9.67
30-34					15.57	16.89	17.61
35-39					58.93	55.36	55.68
40-44					143.39	170.42	210.01
45+					224.72	466.02	694.94
unknown					---	---	---

nr = not reported
* data include less than 5 years

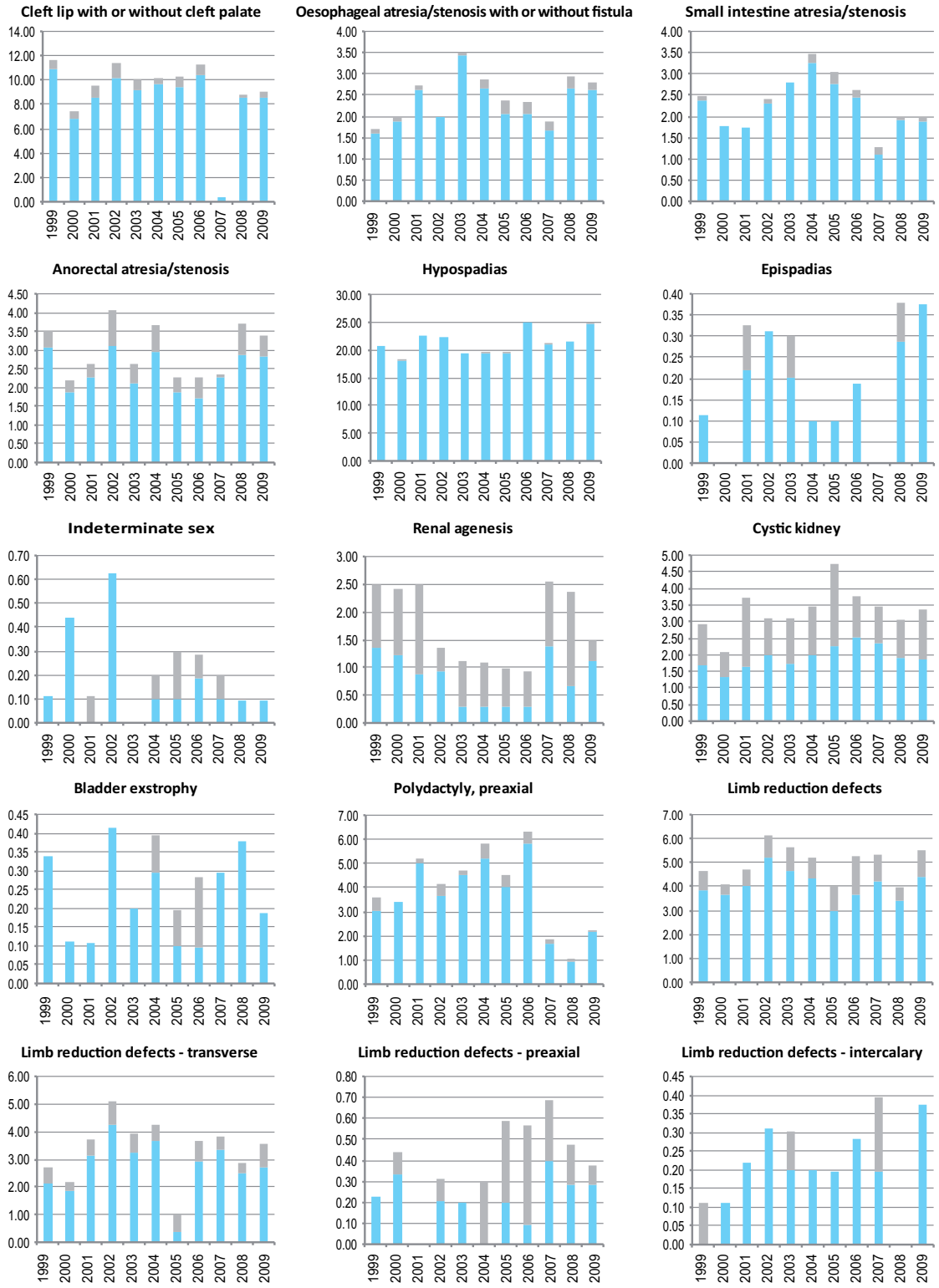
Sweden

Time trends 1999-2009 (Birth prevalence rates per 10,000)



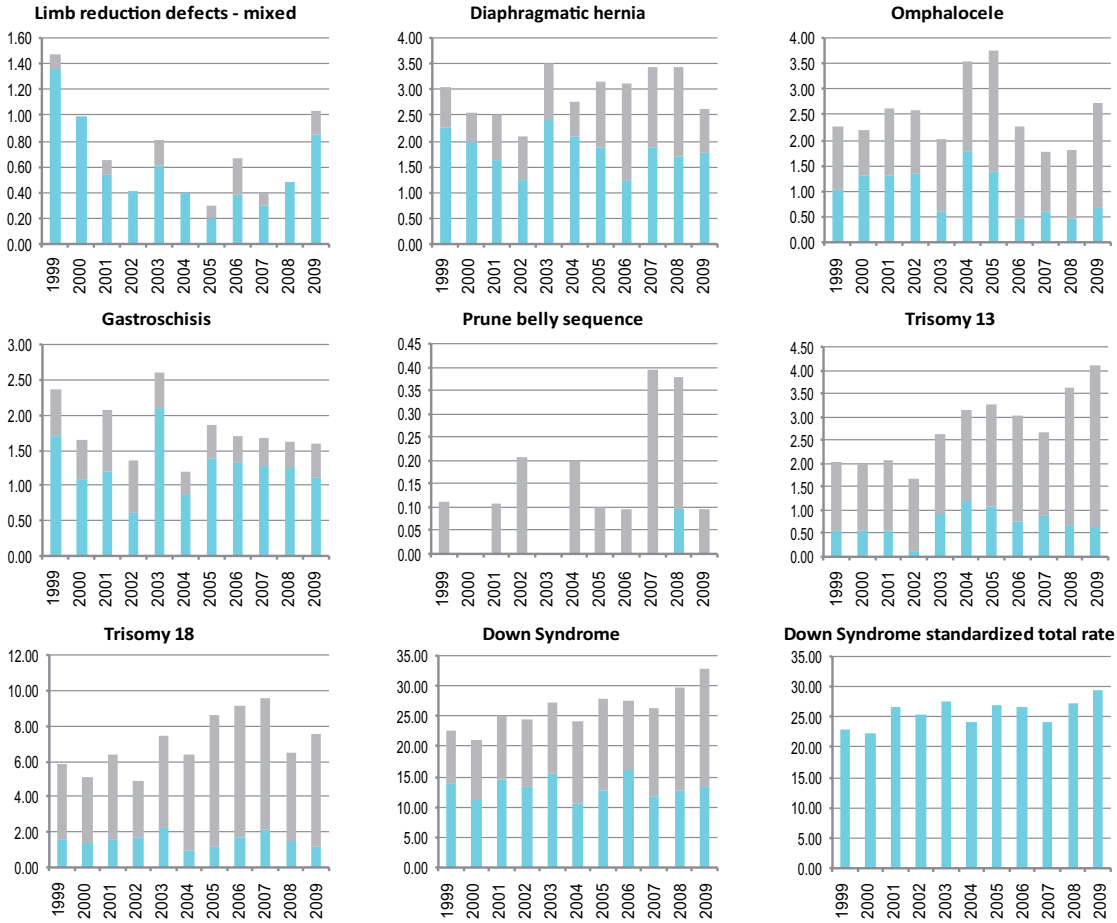
Note: L+S rates, ToP rates

Sweden



Note: L+S rates, ToP rates

Sweden



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
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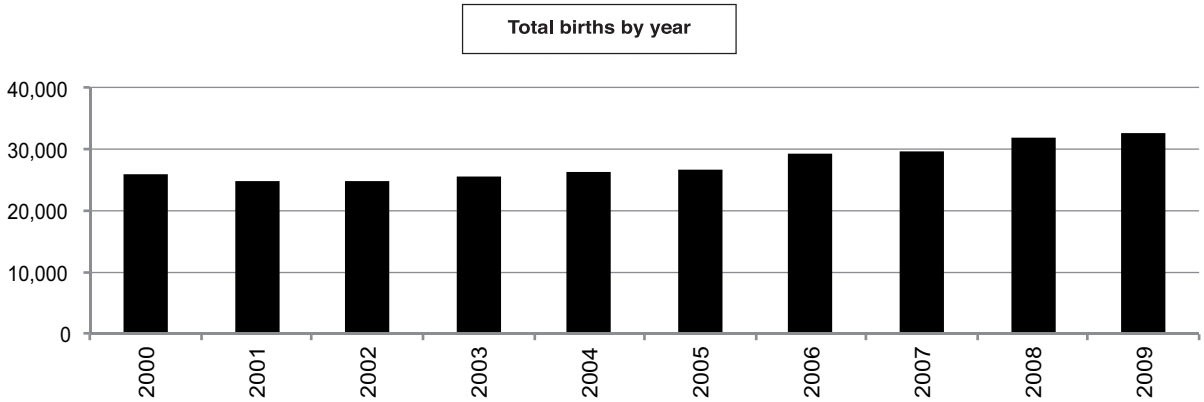
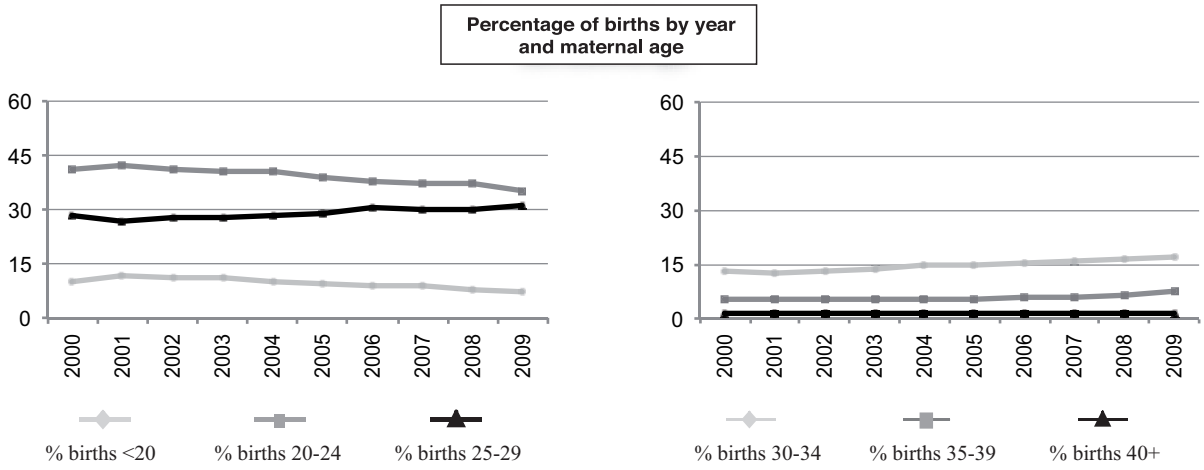
E-mail: werteleckiomni@gmail.com
yevtushokl@gmail.com
rivneomni2@gmail.com
Website: http://www.ibis-birthdefects.org/

Ukraine: OMNI-Net





Ukraine: OMNI-Net, 2009

Live births (LB)	32,289
Stillbirths (SB)	197
Total births	32,486
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	6	18	7.70
Spina bifida	14	1	19	10.47
Encephalocele	3	0	3	1.85
Microcephaly	19	1	nr	6.16
Holoprosencephaly	6	2	nr	2.46
Hydrocephaly	16	7	nr	7.08
Anophthalmos	2	0	nr	0.62
Microphthalmos	6	0	nr	1.85
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	1	0	nr	0.31
Microtia	11	0	nr	3.39
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	8	0	nr	2.46
Tetralogy of Fallot	12	1	nr	4.00
Hypoplastic left heart syndrome	10	0	nr	3.08
Coarctation of aorta	5	0	nr	1.54
Choanal atresia, bilateral	1	0	nr	0.31
Cleft palate without cleft lip	26	0	nr	8.00
Cleft lip with or without cleft palate	25	1	nr	8.00
Oesophageal atresia/stenosis with or without fistula	6	0	nr	1.85
Small intestine atresia/stenosis	4	1	nr	1.54
Anorectal atresia/stenosis	6	0	nr	1.85
Undescended testis (36 weeks of gestation or later)	97	0	nr	29.86
Hypospadias	11	0	nr	3.39
Epispadias	0	0	nr	0.00
Indeterminate sex	1	0	nr	0.31
Renal agenesis	2	0	nr	0.62
Cystic kidney	20	3	nr	7.08
Bladder exstrophy	3	0	nr	0.92
Polydactyly, preaxial	14	0	nr	4.31
Total Limb reduction defects (include unspecified)	15	0	nr	4.62
Transverse	11	0	nr	3.39
Preaxial	1	0	nr	0.31
Postaxial	1	0	nr	0.31
Intercalary	0	0	nr	0.00
Mixed	1	0	nr	0.31
Unspecified	0	0	nr	0.00
Diaphragmatic hernia	9	3	nr	3.69
Omphalocele	8	1	nr	2.77
Gastroschisis	5	1	nr	1.85
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13	1	0	nr	0.31
Trisomy 18	2	0	nr	0.62
Down syndrome, all ages (include age unknown)	38	0	nr	11.70
<20	0	0	nr	0.00
20-24	7	0	nr	6.11
25-29	9	0	nr	8.82
30-34	7	0	nr	12.65
35-39	6	0	nr	25.37
40-44	7	0	nr	141.13
45+	2	0	nr	555.56
unknown	0	0	nr	---

nr = not reported

Ukraine: OMNI-Net, Previous years rates 2000 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births						**127,547**	**149,606**
Anencephaly						8.31	8.42
Spina bifida						11.45	10.09
Encephalocele						2.12	2.01
Microcephaly						2.74	4.61
Holoprosencephaly						0.55	1.40
Hydrocephaly						5.64	6.15
Anophthalmos						0.08	0.20
Microphthalmos						1.02	1.54
Unspecified Anophthalmos/Microphthalmos						0.00	0.07
Anotia						0.31	0.40
Microtia						1.65	2.41
Unspecified Anotia/Microtia						0.00	0.00
Transposition of great vessels						3.45	3.68
Tetralogy of Fallot						2.12	2.67
Hypoplastic left heart syndrome						0.94	1.67
Coarctation of aorta						1.33	1.67
Choanal atresia, bilateral						0.00	0.07
Cleft palate without cleft lip						4.31	5.95
Cleft lip with or without cleft palate						8.86	8.29
Oesophageal atresia/stenosis with or without fistula						1.49	2.34
Small intestine atresia/stenosis						1.49	1.67
Anorectal atresia/stenosis						2.82	1.87
Undescended testis (36 weeks of gestation or later)						38.81	34.42
Hypospadias						3.14	3.41
Epispadias						0.31	0.07
Indeterminate sex						0.55	0.27
Renal agenesis						0.78	0.80
Cystic kidney						2.04	4.41
Bladder exstrophy						0.86	0.60
Polydactyly, preaxial						2.82	4.81
Total Limb reduction defects (include unspecified)						3.84	3.61
Transverse						2.27	1.87
Preaxial						0.47	0.53
Postaxial						0.24	0.40
Intercalary						0.31	0.27
Mixed						0.24	0.47
Unspecified						0.31	0.00
Diaphragmatic hernia						1.88	2.54
Omphalocele						1.25	1.94
Gastroschisis						1.02	1.80
Unspecified Omphalocele/Gastroschisis						0.00	0.00
Prune belly sequence						0.00	0.00
Trisomy 13						0.16	0.40
Trisomy 18						0.31	0.40
Down syndrome, all ages (include age unknown)						12.31	13.03
<20						7.18	11.77
20-24						7.61	6.27
25-29						9.28	8.60
30-34						16.38	15.04
35-39						30.40	37.03
40-44						102.62	142.72
45+						816.33	326.80
unknown						---	---

nr = not reported

Ukraine: OMNI-Net

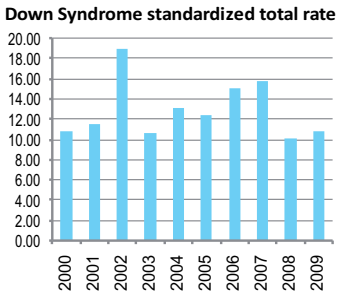
Time trends 2000-2009 (Birth prevalence rates per 10,000)

Note: L+S rates, ToP rates

Ukraine: OMNI-Net

Note: L+S rates, ToP rates

Ukraine: OMNI-Net



Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS

Congenital Anomaly Register and Information System for Wales

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

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

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

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

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

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

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

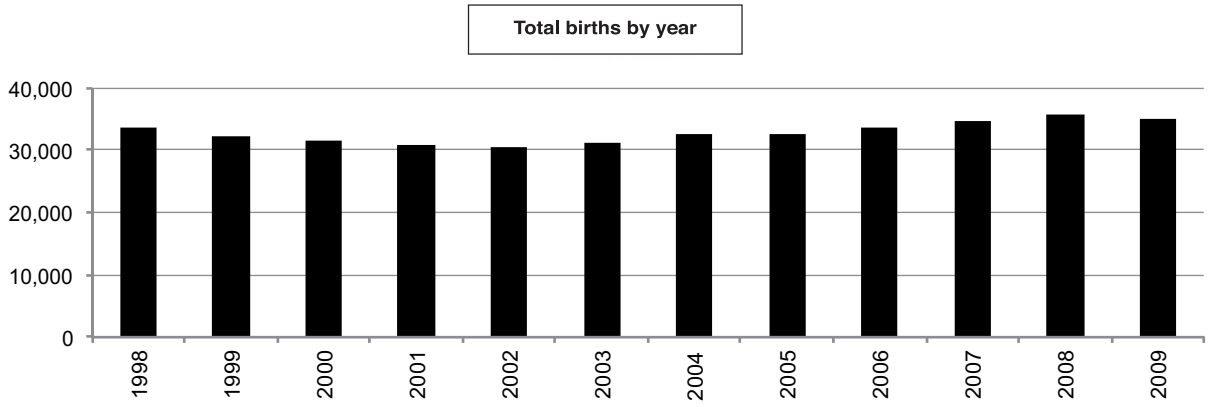
Exposure Data Availability:
Maternal drugs, folic acid dosage and timing, maternal and paternal diseases and occupations

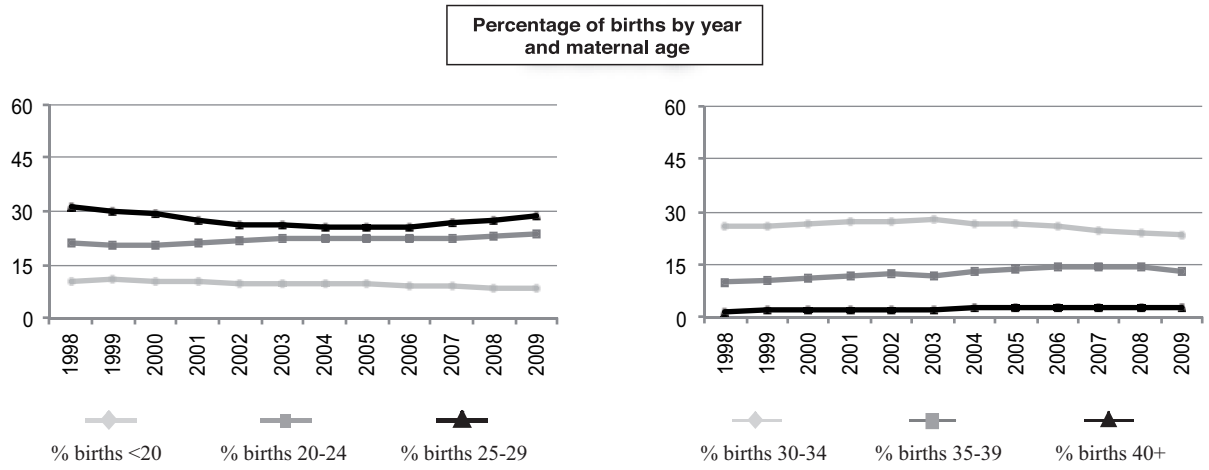
Denominators and Controls Information:
Data obtained from Office for National Statistics

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

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

United Kingdom-Wales: CARIS





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	50	98.0	Cystic kidney	20	21.5
Spina bifida	47	69.1	Limb reduction defects	34	35.4
Encephalocele	17	81.0	Diaphragmatic hernia	10	24.4
Holoprosencephaly	13	92.9	Omphalocele	27	60.0
Hydrocephaly	54	55.1	Gastroschisis	4	7.5
Hypoplastic left heart syndrome	14	42.4	Trisomy 13	20	83.3
Cleft palate without cleft lip	10	11.8	Trisomy 18	46	70.8
Cleft lip with or without cleft palate	22	16.1	Down syndrome	115	49.6
Renal agenesis	18	85.7			

Total ToPs with births defects = 566 (Ratio ToPs/Births: 5.36 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

United Kingdom-Wales: CARIS, 2009

Live births (LB)	34,937
Stillbirths (SB)	180
Total births	35,117
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	20	5.70
Spina bifida	9	≤ 3	16	nc
Encephalocele	≤ 3	0	7	nc
Microcephaly	9	0	≤ 3	nc
Holoprosencephaly	≤ 3	0	5	nc
Hydrocephaly	13	≤ 3	17	nc
Anophthalmos	0	0	0	0.00
Microphthalmos	≤ 3	0	0	nc
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	≤ 3	nc
Microtia	≤ 3	0	0	nc
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	19	≤ 3	≤ 3	nc
Tetralogy of Fallot	17	0	≤ 3	nc
Hypoplastic left heart syndrome	4	≤ 3	≤ 3	nc
Coarctation of aorta	17	0	0	4.84
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	24	0	≤ 3	nc
Cleft lip with or without cleft palate	42	0	8	14.24
Oesophageal atresia/stenosis with or without fistula	9	≤ 3	≤ 3	nc
Small intestine atresia/stenosis	≤ 3	0	0	nc
Anorectal atresia/stenosis	15	0	≤ 3	nc
Undescended testis (36 weeks of gestation or later)	37	0	0	10.54
Hypospadias	76	0	0	21.64
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	≤ 3	0	7	nc
Cystic kidney	16	0	7	6.55
Bladder exstrophy	≤ 3	0	0	nc
Polydactyly, preaxial	≤ 3	≤ 3	≤ 3	nc
Total Limb reduction defects (include unspecified)	20	0	14	9.68
Transverse	11	0	4	4.27
Preaxial	≤ 3	0	5	nc
Postaxial	≤ 3	0	≤ 3	nc
Intercalary	≤ 3	0	≤ 3	nc
Mixed	≤ 3	0	≤ 3	nc
Unspecified	≤ 3	0	≤ 3	nc
Diaphragmatic hernia	13	0	≤ 3	nc
Omphalocele	7	0	11	5.13
Gastroschisis	18	0	≤ 3	nc
Unspecified Omphalocele/Gastroschisis	0	0	≤ 3	nc
Prune belly sequence	≤ 3	0	0	nc
Trisomy 13	≤ 3	0	6	nc
Trisomy 18	≤ 3	4	10	nc
Down syndrome, all ages (include age unknown)	40	≤ 3	45	nc
<20	0	0	≤ 3	nc
20-24	15	0	≤ 3	nc
25-29	5	0	≤ 3	nc
30-34	6	0	11	20.61
35-39	12	0	22	73.07
40-44	≤ 3	≤ 3	7	nc
45+	0	0	0	0.00
unknown	0	0	0	---

nc = not calculable
(*) According to national guidelines number for LB, SB and ToPs ≤ 3 should not be explicitly published

United Kingdom-Wales: CARIS, Previous years rates 1998 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999*	2000-2004	2005-2009
Total births					**65,886**	**156,423**	**172,035**
Anencephaly					8.35	6.90	4.94
Spina bifida					7.89	8.25	6.68
Encephalocele					2.73	1.79	2.27
Microcephaly					6.83	6.58	4.48
Holoprosencephaly					1.06	1.79	1.34
Hydrocephaly					11.84	9.46	8.43
Anophthalmos					0.91	0.19	0.17
Microphthalmos					1.97	2.05	1.34
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00
Anotia					0.61	0.06	0.58
Microtia					0.61	0.70	0.52
Unspecified Anotia/Microtia					0.00	0.00	0.00
Transposition of great vessels					5.62	4.73	4.30
Tetralogy of Fallot					3.64	2.81	4.36
Hypoplastic left heart syndrome					3.49	3.58	3.08
Coarctation of aorta					6.37	6.71	5.35
Choanal atresia, bilateral					0.15	0.19	0.29
Cleft palate without cleft lip					10.32	9.40	8.89
Cleft lip with or without cleft palate					11.38	9.91	12.03
Oesophageal atresia/stenosis with or without fistula					3.34	3.45	2.91
Small intestine atresia/stenosis					2.28	1.60	2.09
Anorectal atresia/stenosis					4.71	4.48	3.72
Undescended testis (36 weeks of gestation or later)					28.23	8.06	10.64
Hypospadias					27.93	30.30	27.26
Epispadias					0.46	0.45	0.23
Indeterminate sex					0.15	0.58	0.93
Renal agenesis					3.34	1.85	2.09
Cystic kidney					10.93	10.29	8.78
Bladder exstrophy					0.61	0.19	0.35
Polydactyly, preaxial					0.61	1.47	0.81
Total Limb reduction defects (include unspecified)					12.14	9.40	9.18
Transverse					5.46	4.41	4.94
Preaxial					2.28	1.09	1.69
Postaxial					0.61	0.51	0.29
Intercalary					1.52	1.73	1.40
Mixed					0.76	1.21	0.52
Unspecified					1.52	1.21	0.47
Diaphragmatic hernia					3.49	3.71	4.01
Omphalocele					3.04	4.09	4.30
Gastroschisis					5.31	5.82	6.05
Unspecified Omphalocele/Gastroschisis					0.61	0.58	0.35
Prune belly sequence					0.15	0.19	0.12
Trisomy 13					2.12	2.56	2.03
Trisomy 18					4.86	4.67	6.05
Down syndrome, all ages (include age unknown)					19.12	20.71	22.44
<20					12.83	7.70	5.91
20-24					8.06	6.19	11.50
25-29					11.93	10.97	7.74
30-34					15.82	17.30	18.83
35-39					56.93	54.12	59.56
40-44					140.85	174.21	139.25
45+					0.00	388.89	313.90
unknown					---	---	---

* data include less than 5 years

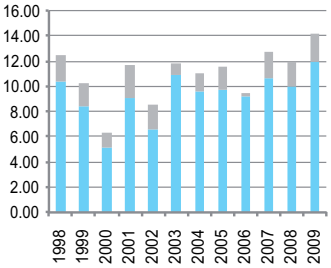
United Kingdom-Wales: CARIS

Time trends 1998-2009 (Birth prevalence rates per 10,000)

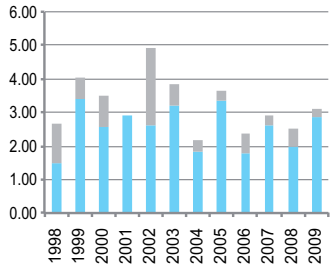
Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS

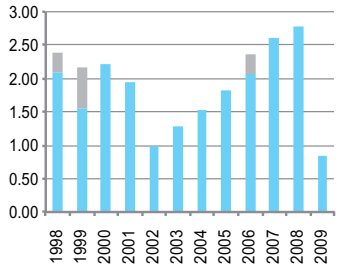
Cleft lip with or without cleft palate



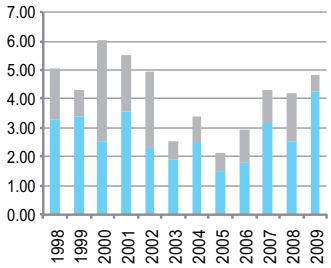
Oesophageal atresia/stenosis with or without fistula



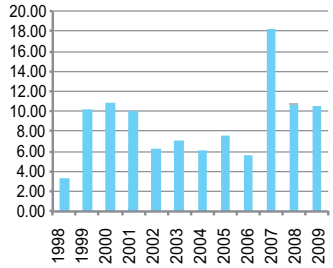
Small intestine atresia/stenosis



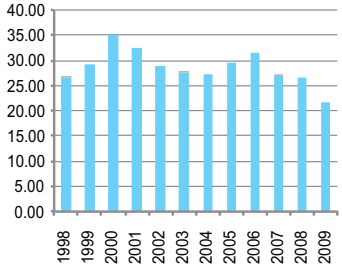
Anorectal atresia/stenosis



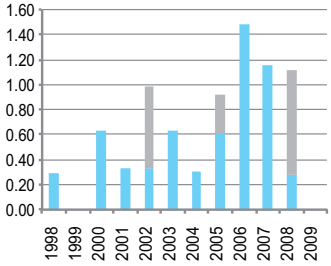
Undescended testis



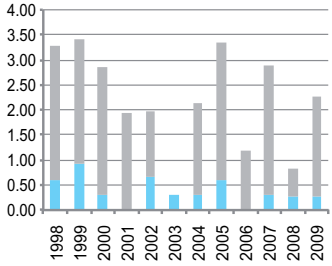
Hypospadias



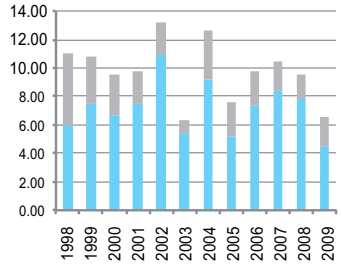
Indeterminate sex



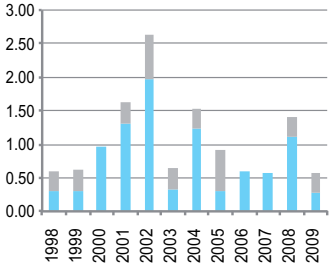
Renal agenesis



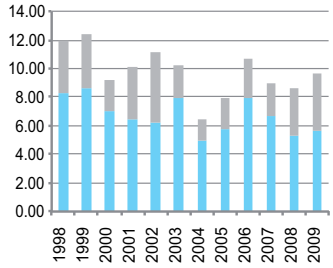
Cystic kidney



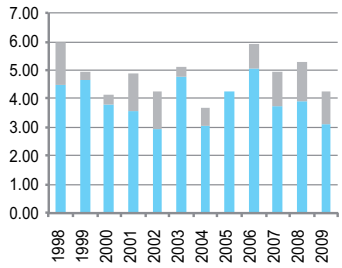
Polydactyly, preaxial



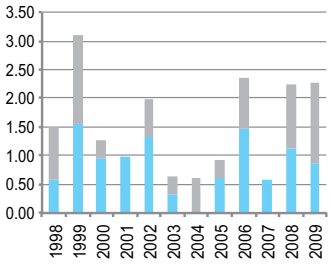
Limb reduction defects



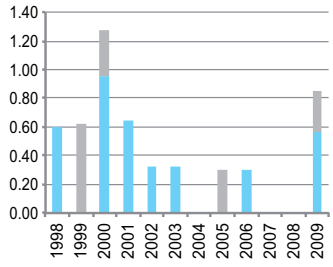
Limb reduction defects - transverse



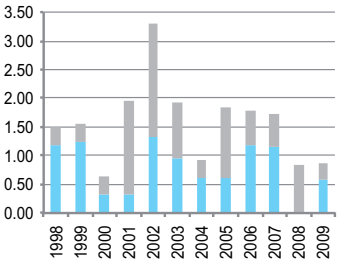
Limb reduction defects - preaxial



Limb reduction defects - postaxial

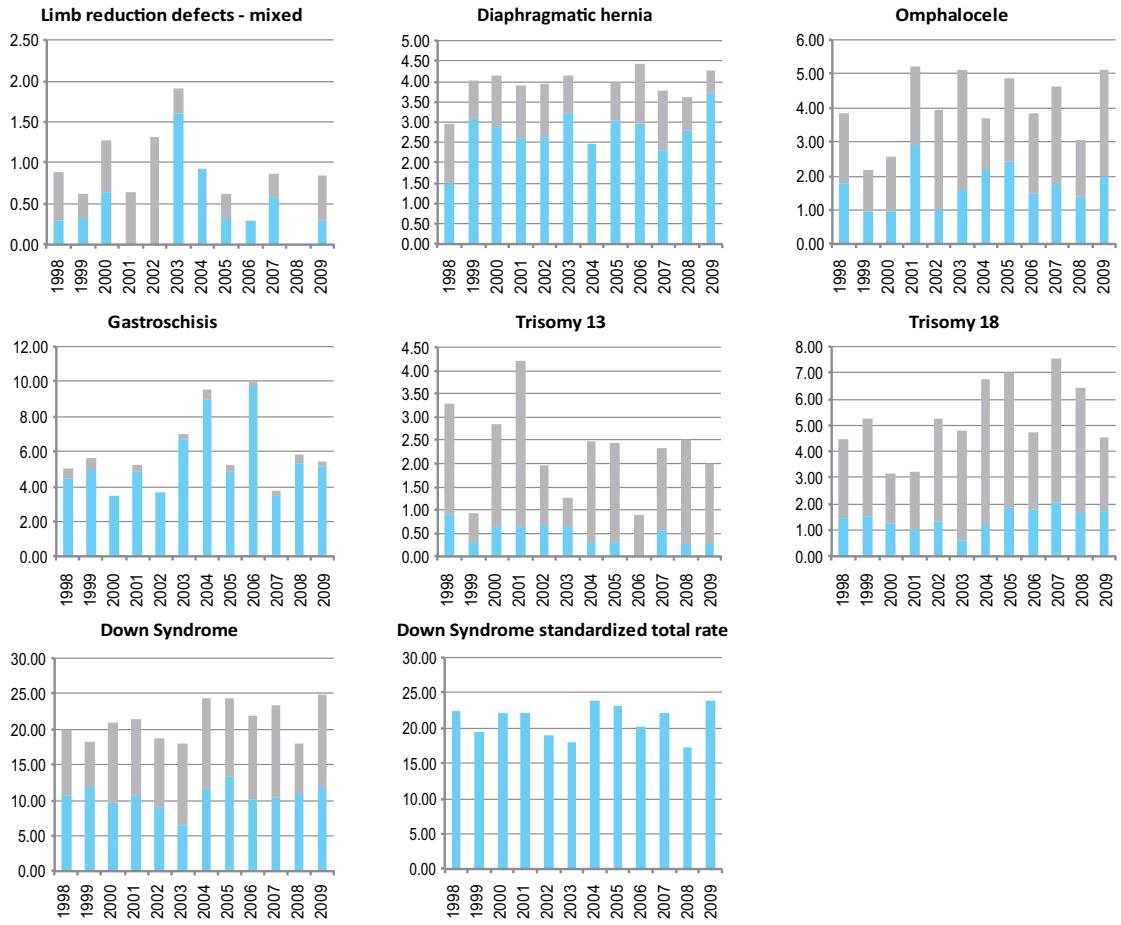


Limb reduction defects - intercalary



Note: L+S rates, ToP rates

United Kingdom-Wales: CARIS



Note: L+S rates, ToP rates

USA-Atlanta: MACDP
Metropolitan Atlanta Congenital Defects Program

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

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

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

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

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

Addresses and Staff:
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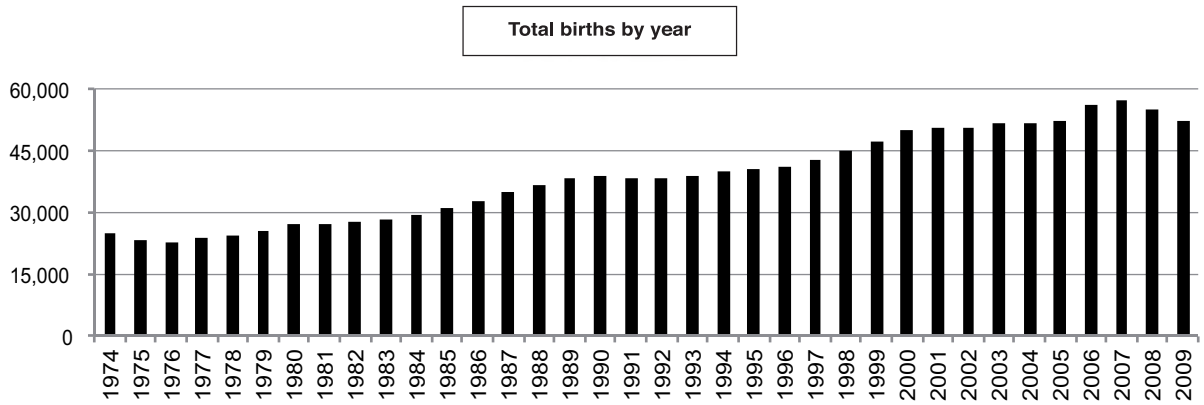
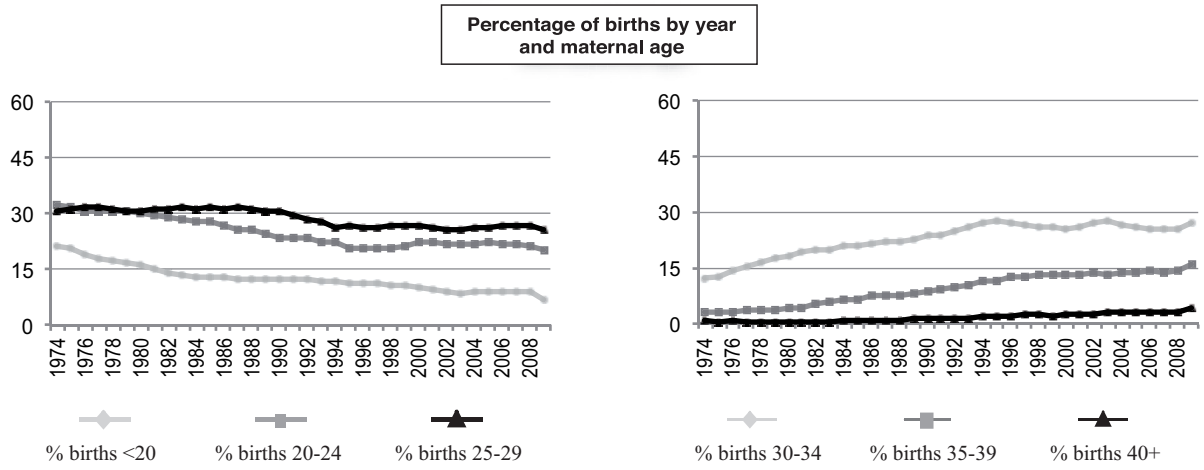
E-mail: csiffel@cdc.gov

USA-Atlanta: MACDP





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	40	67.8	Cystic kidney	16	14.2
Spina bifida	19	26.4	Limb reduction defects	9	10.8
Encephalocele	8	33.3	Diaphragmatic hernia	6	12.5
Holoprosencephaly	5	17.2	Omphalocele	11	23.9
Hydrocephaly	11	8.1	Gastroschisis	5	6.3
Hypoplastic left heart syndrome	4	11.1	Trisomy 13	15	60.0
Cleft palate without cleft lip	3	3.5	Trisomy 18	39	48.8
Cleft lip with or without cleft palate	15	9.1	Down syndrome	51	18.7
Renal agenesis	5	20.8			

Total ToPs with births defects = not reported
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Atlanta: MACDP, 2009

Live births (LB)	51,926
Stillbirths (SB)	420
Total births	52,346
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	4	20	5.16
Spina bifida	20	2	6	5.35
Encephalocele	2	1	4	1.34
Microcephaly	26	0	0	4.97
Holoprosencephaly	7	4	4	2.87
Hydrocephaly	45	7	5	10.89
Anophthalmos	1	0	0	0.19
Microphthalmos	5	0	0	0.96
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.38
Microtia	9	0	0	1.72
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	25	2	2	5.54
Tetralogy of Fallot	28	0	1	5.54
Hypoplastic left heart syndrome	10	5	3	3.44
Coarctation of aorta	32	0	1	6.30
Choanal atresia, bilateral	2	0	0	0.38
Cleft palate without cleft lip	33	1	3	7.07
Cleft lip with or without cleft palate	48	1	12	11.65
Oesophageal atresia/stenosis with or without fistula	16	0	0	3.06
Small intestine atresia/stenosis	14	1	0	2.87
Anorectal atresia/stenosis	23	0	0	4.39
Undescended testis (36 weeks of gestation or later)	13	0	0	2.48
Hypospadias	21	0	0	4.01
Epispadias	0	0	0	0.00
Indeterminate sex	4	1	1	1.15
Renal agenesis	11	0	4	2.87
Cystic kidney	44	2	9	10.51
Bladder exstrophy	3	0	0	0.57
Polydactyly, preaxial	16	0	0	3.06
Total Limb reduction defects (include unspecified)	27	3	5	6.69
Transverse	14	2	3	3.63
Preaxial	6	0	2	1.53
Postaxial	0	0	0	0.00
Intercalary	3	1	0	0.76
Mixed	0	0	0	0.00
Unspecified	3	0	0	0.57
Diaphragmatic hernia	16	0	4	3.82
Omphalocele	13	1	7	4.01
Gastroschisis	16	1	3	3.82
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	2	0.38
Trisomy 13	2	1	11	2.67
Trisomy 18	12	9	22	8.21
Down syndrome, all ages (include age unknown)	61	1	28	17.19
<20	3	0	0	8.32
20-24	9	0	0	8.49
25-29	13	0	2	11.19
30-34	13	0	5	12.82
35-39	15	1	10	30.89
40-44	5	0	9	67.44
45+	2	0	0	104.71
unknown	1	0	2	---

nr = not reported
(*) ToP cases include cases with pregnancy outcome unknown

USA-Atlanta: MACDP, Previous years rates 1974 - 2009

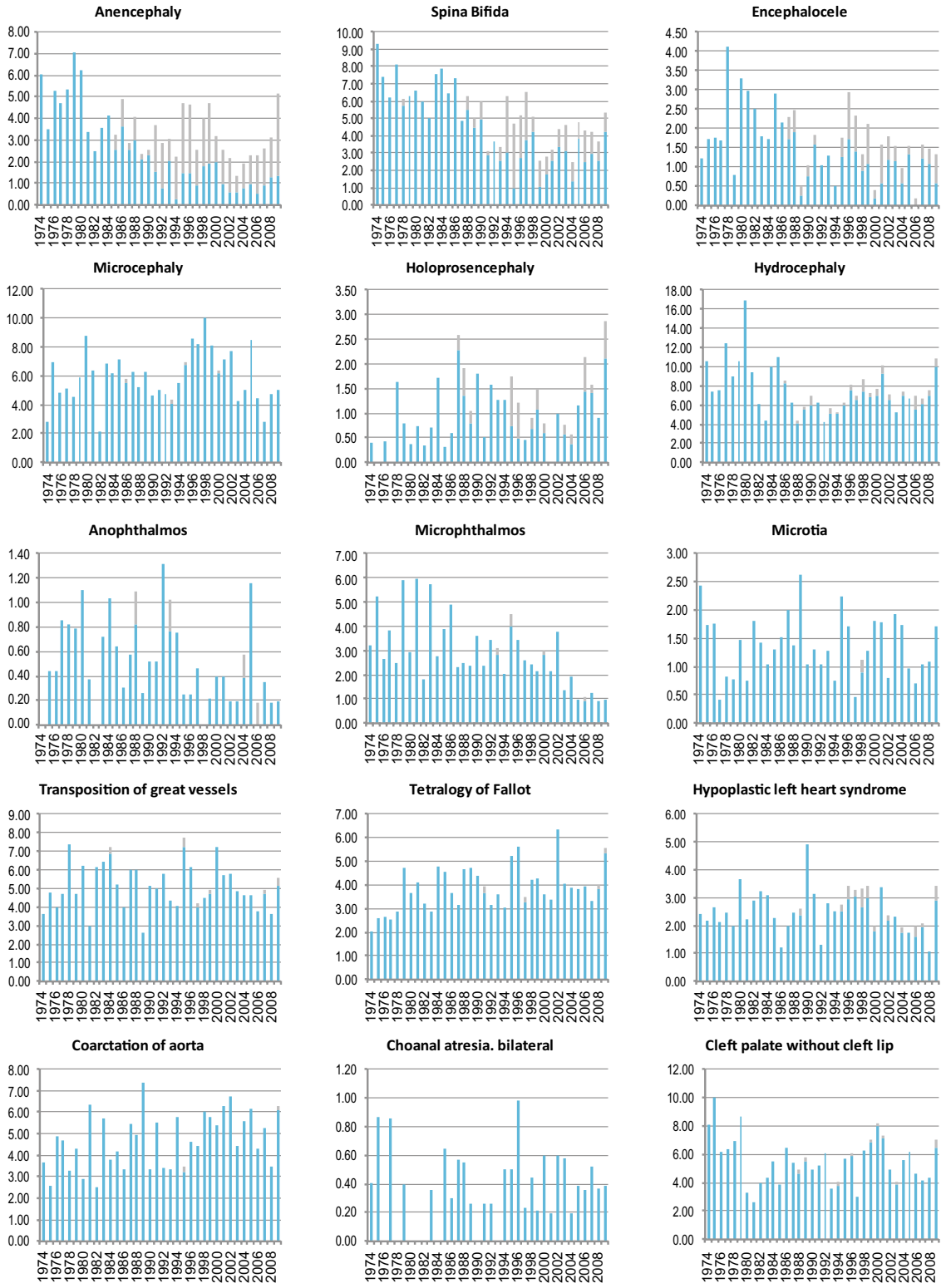
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Total births	**143,922**	**139,240**	**173,520**	**194,162**	**216,010**	**254,792**	**272,668**
Anencephaly	5.35	3.95	3.46	2.88	4.12	2.24	3.08
Spina bifida	7.23	6.61	5.94	4.48	4.77	3.49	4.44
Encephalocele	1.88	2.44	2.02	1.13	2.08	1.26	1.21
Microcephaly	5.00	6.03	6.11	4.84	8.38	6.08	5.02
Holoprosencephaly	0.56	0.79	1.33	1.29	1.16	0.63	1.72
Hydrocephaly	9.59	9.26	7.03	5.67	7.45	7.46	7.70
Anophthalmos	0.56	0.65	0.58	0.82	0.23	0.35	0.40
Microphthalmos	3.89	3.81	3.11	2.88	2.96	2.43	1.03
Unspecified Anophthalmos/Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.21	0.22	0.06	0.21	0.19	0.27	0.18
Microtia	1.32	1.29	1.79	1.08	1.34	1.61	1.10
Unspecified Anotia/Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	4.86	5.82	4.73	4.84	5.42	5.61	4.47
Tetralogy of Fallot	2.92	3.73	4.15	3.61	4.54	4.24	4.11
Hypoplastic left heart syndrome	2.29	3.02	2.13	2.94	3.24	2.39	2.05
Coarctation of aorta	3.89	4.24	5.13	4.27	4.91	5.69	5.06
Choanal atresia, bilateral	0.42	0.07	0.46	0.21	0.46	0.43	0.40
Cleft palate without cleft lip	7.71	3.95	5.30	4.74	5.65	6.00	5.24
Cleft lip with or without cleft palate	11.46	11.35	9.11	9.37	9.44	8.75	9.68
Oesophageal atresia/stenosis with or without fistula	2.29	2.51	2.36	2.16	2.04	2.04	2.16
Small intestine atresia/stenosis	1.46	1.65	1.67	1.80	1.67	1.96	2.27
Anorectal atresia/stenosis	4.66	3.52	4.26	3.71	3.47	3.26	3.52
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	13.20*	18.17	9.98
Hypospadias	1.25	1.58	4.61	4.79	8.29	8.40	5.43
Epispadias	0.97	0.86	0.63	0.62	0.42	0.43	0.48
Indeterminate sex	2.29	1.80	1.15	1.13	1.34	1.65	1.50
Renal agenesis	2.08	1.87	1.21	1.34	1.16	1.10	1.21
Cystic kidney	2.43	2.73	4.21	5.10	5.83	6.32	6.56
Bladder exstrophy	0.49	0.22	0.23	0.36	0.09	0.12	0.15
Polydactyly, preaxial	1.95	1.87	2.59	3.35	2.64	2.16	2.31
Total Limb reduction defects (include unspecified)	6.18	4.45	4.61	4.79	6.34	5.49	4.55
Transverse	3.68	3.09	2.77	3.45	3.38	3.22	2.35
Preaxial	1.18	0.57	0.81	0.82	1.20	0.94	0.66
Postaxial	0.21	0.22	0.35	0.26	0.32	0.20	0.26
Intercalary	0.63	0.22	0.29	0.05	0.28	0.24	0.40
Mixed	0.07	0.36	0.29	0.15	0.74	0.78	0.59
Unspecified	0.42	0.00	0.12	0.05	0.42	0.08	0.26
Diaphragmatic hernia	2.57	2.30	2.82	2.37	2.18	2.83	2.93
Omphalocele	3.89	3.16	3.11	2.58	2.45	1.96	2.46
Gastroschisis	1.67	1.87	2.31	2.73	1.71	3.18	4.36
Unspecified Omphalocele/Gastroschisis	0.00	0.00	0.06	0.00	0.00	0.00	0.00
Prune belly sequence	0.63	0.50	0.46	0.36	0.32	0.47	0.44
Trisomy 13	1.18	1.08	1.67	1.18	1.94	1.96	1.54
Trisomy 18	0.63	1.94	2.07	2.47	4.44	4.71	4.25
Down syndrome, all ages (include age unknown)	8.82	10.99	10.37	12.67	17.68	17.58	16.43
<20	nr	7.01	6.48	7.23	10.48	6.38	8.40
20-24	nr	6.68	8.65	6.95	10.21	4.99	8.17
25-29	nr	8.29	6.82	7.22	8.01	7.96	7.65
30-34	nr	16.81	12.67	11.70	13.55	15.07	13.87
35-39	nr	20.65	22.97	31.73	43.33	48.90	35.62
40-44	nr	80.32	66.62	70.80	137.67	119.17	94.14
45+	nr	0.00	0.00	487.80	251.26	121.21	104.71
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

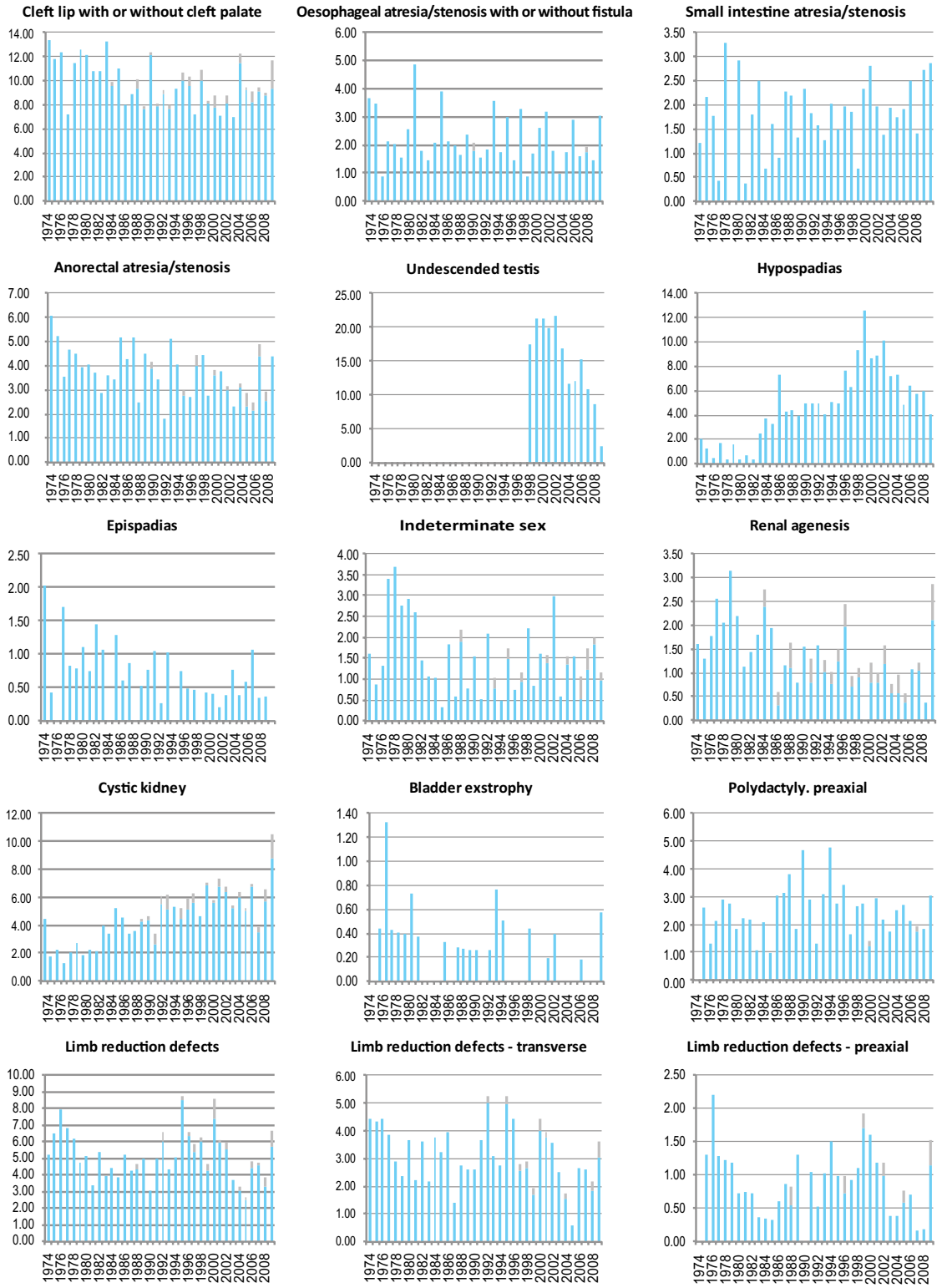
USA-Atlanta: MACDP

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



Note: L+S rates, ToP rates

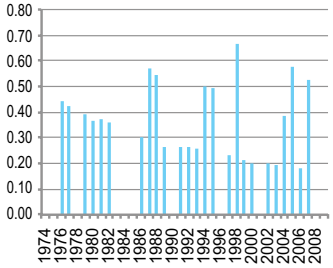
USA-Atlanta: MACDP



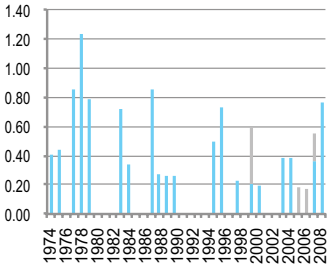
Note: L+S rates, ToP rates

USA-Atlanta: MACDP

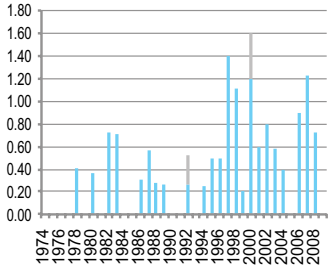
Limb reduction defects - postaxial



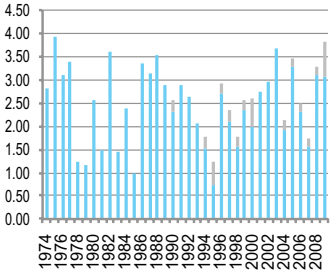
Limb reduction defects - intercalary



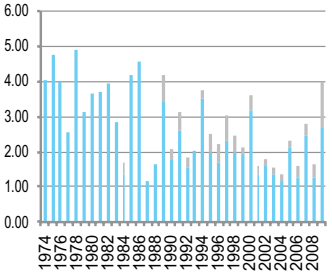
Limb reduction defects - mixed



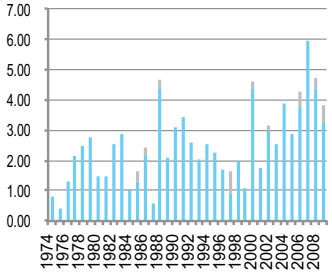
Diaphragmatic hernia



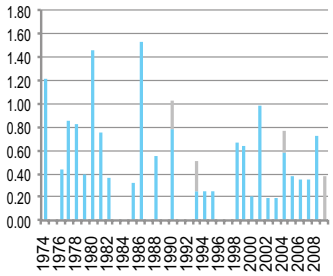
Omphalocele



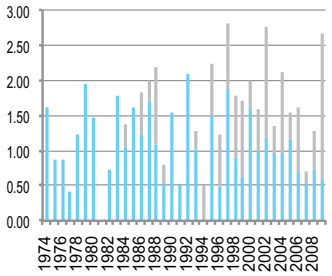
Gastroschisis



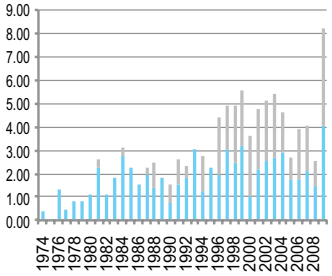
Prune belly sequence



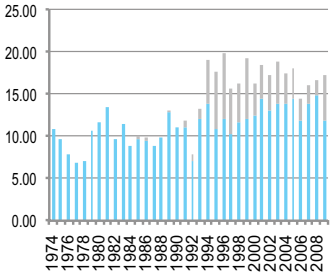
Trisomy 13



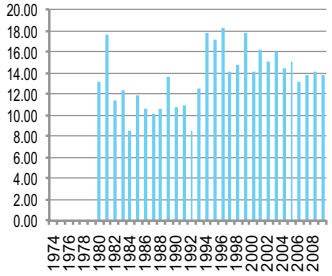
Trisomy 18



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.

Addresses and Staff:
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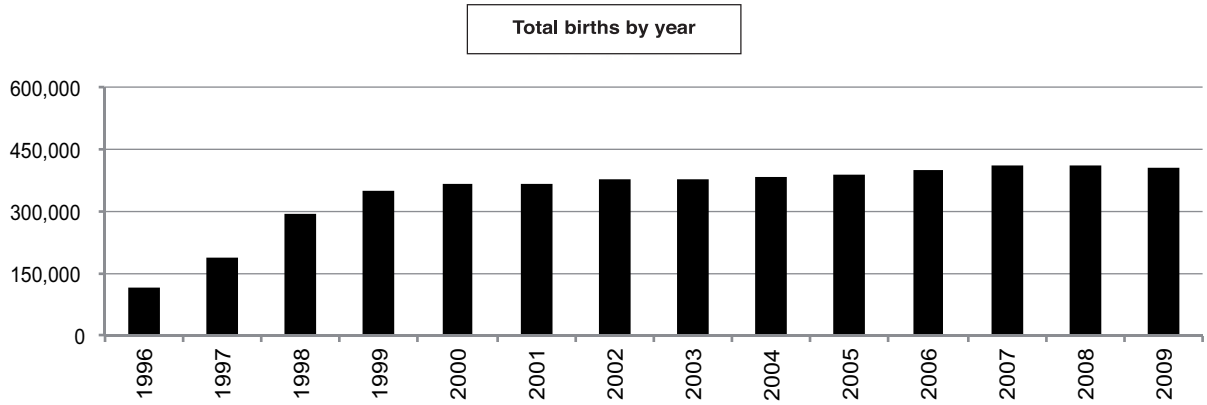
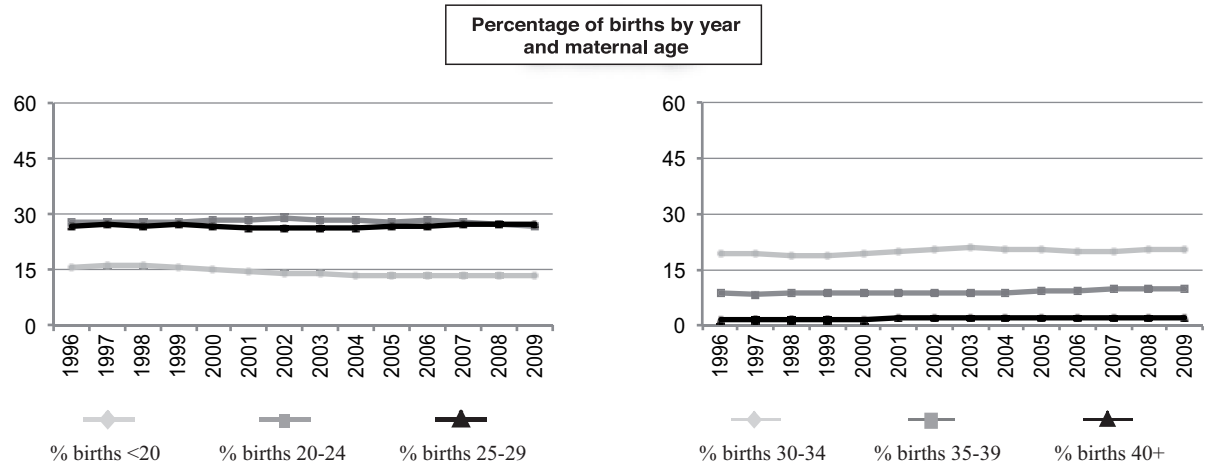
Website: http://www.dshs.state.tx.us/birthdefects/

USA-Texas: BDES





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	103	31.7	Cystic kidney	15	2.1
Spina bifida	20	4.5	Limb reduction defects	22	3.2
Encephalocele	18	15.1	Diaphragmatic hernia	3	0.8
Holoprosencephaly	9	6.8	Omphalocele	16	6.5
Hydrocephaly	13	1.6	Gastroschisis	11	1.5
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	24	16.1
Cleft palate without cleft lip	7	1.0	Trisomy 18	63	18.9
Cleft lip with or without cleft palate	36	2.9	Down syndrome	58	3.5
Renal agenesis	21	8.7			

Total ToPs with births defects = 577 (Ratio ToPs/Births: 0.47 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Texas: BDES, 2009

Live births (LB)	401,599
Stillbirths (SB)	2,270
Total births	403,869
Number of terminations of pregnancy (ToP) for birth defects	207

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	42	40	41	3.05
Spina bifida	139	5	9	3.79
Encephalocele	25	5	7	0.92
Microcephaly	525	2	2	13.10
Holoprosencephaly	27	3	4	0.84
Hydrocephaly	258	10	3	6.71
Anophthalmos	12	1	0	0.32
Microphthalmos	97	2	0	2.45
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	1	1	0.12
Microtia	129	0	0	3.19
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	221	0	0	5.47
Tetralogy of Fallot	149	0	0	3.69
Hypoplastic left heart syndrome	86	0	0	2.13
Coarctation of aorta	198	0	0	4.90
Choanal atresia, bilateral	54	1	0	1.36
Cleft palate without cleft lip	218	6	2	5.60
Cleft lip with or without cleft palate	345	19	10	9.26
Oesophageal atresia/stenosis with or without fistula	88	0	0	2.18
Small intestine atresia/stenosis	72	0	0	1.78
Anorectal atresia/stenosis	187	6	5	4.90
Undescended testis (36 weeks of gestation or later) (§)	495	1	0	12.28
Hypospadias	682	0	0	16.89
Epispadias	38	0	0	0.94
Indeterminate sex	10	17	5	0.79
Renal agenesis	65	2	9	1.88
Cystic kidney	262	4	5	6.71
Bladder exstrophy	4	0	0	0.10
Polydactyly, preaxial	165	1	0	4.11
Total Limb reduction defects (include unspecified)	204	11	5	5.45
Transverse	106	6	5	2.90
Preaxial	45	1	0	1.14
Postaxial	7	0	0	0.17
Intercalary	5	1	0	0.15
Mixed	30	2	0	0.79
Unspecified	11	1	0	0.30
Diaphragmatic hernia	106	3	1	2.72
Omphalocele	64	20	5	2.20
Gastroschisis	223	13	4	5.94
Unspecified Omphalocele/Gastroschisis	13	4	6	0.57
Prune belly sequence	5	0	1	0.15
Trisomy 13	32	12	9	1.31
Trisomy 18	60	28	25	2.80
Down syndrome, all ages (include age unknown)	515	12	22	13.59
<20	43	0	0	8.04
20-24	55	1	0	5.19
25-29	85	1	5	8.21
30-34	91	3	2	11.59
35-39	127	5	10	35.74
40-44	102	2	5	132.19
45+	12	0	0	237.15
unknown	0	0	0	---

(*) Only definite diagnosed cases are reported. Data for 2009 are still provisional.
(§) Undescended testes is not coded in infants less than 36 weeks gestation unless another reportable defect is present or there was a medical/surgical intervention for this problem. Only 4.5% are <36 weeks gestation.

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

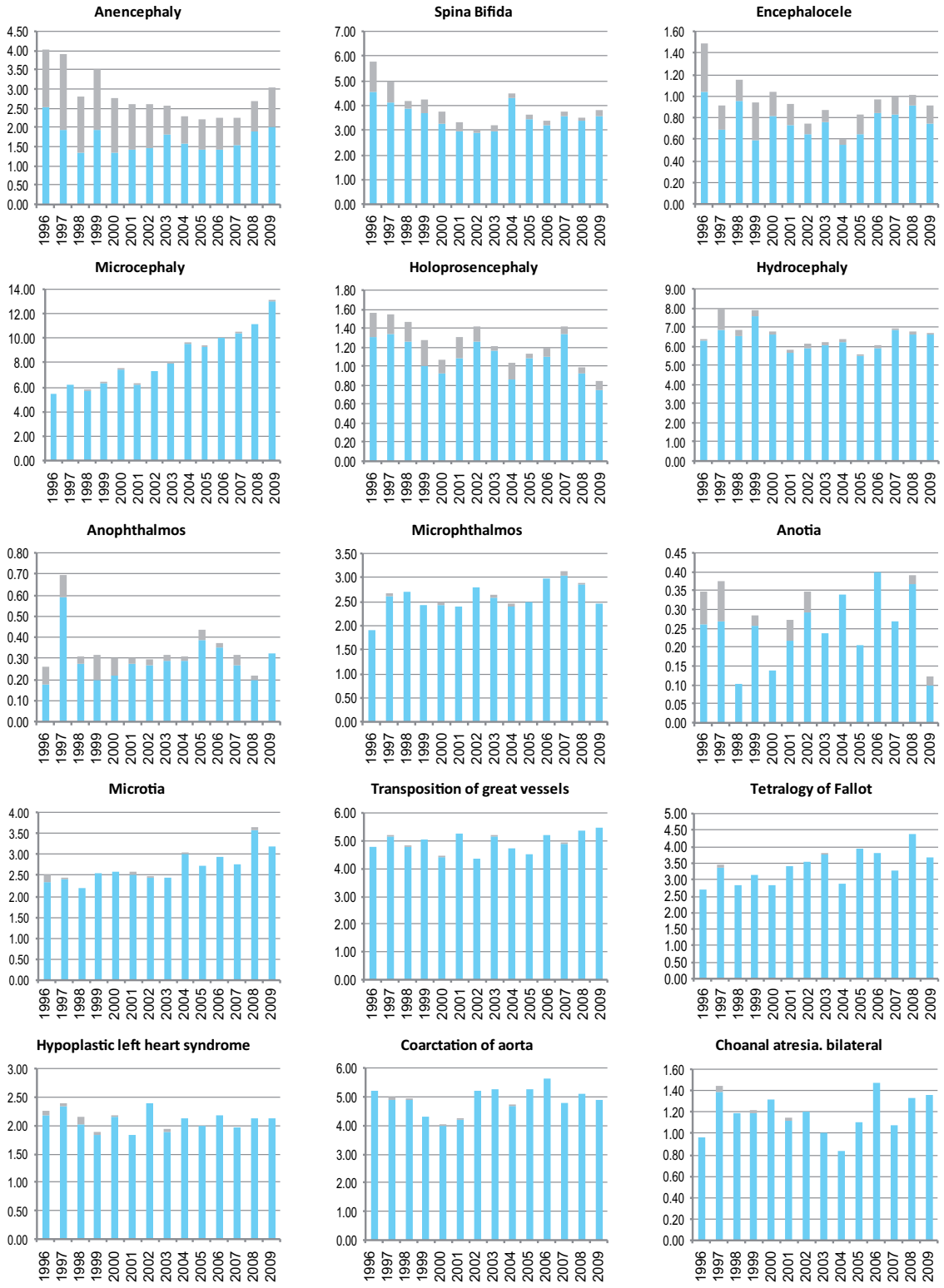
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999*	2000-2004	2005-2009
Total births					**947,252**	**1,870,900**	**2,010,927**
Anencephaly					3.42	2.57	2.50
Spina bifida					4.54	3.58	3.62
Encephalocele					1.07	0.83	0.94
Microcephaly					6.01	7.73	10.85
Holoprosencephaly					1.43	1.21	1.11
Hydrocephaly					7.41	6.25	6.42
Anophthalmos					0.38	0.30	0.33
Microphthalmos					2.49	2.55	2.80
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00
Anotia					0.25	0.27	0.28
Microtia					2.42	2.64	3.05
Unspecified Anotia/Microtia					0.00	0.00	0.00
Transposition of great vessels					4.99	4.81	5.12
Tetralogy of Fallot					3.05	3.29	3.82
Hypoplastic left heart syndrome					2.11	2.10	2.08
Coarctation of aorta					4.76	4.68	5.14
Choanal atresia, bilateral					1.22	1.10	1.27
Cleft palate without cleft lip					5.81	5.37	5.74
Cleft lip with or without cleft palate					10.83	10.70	10.45
Oesophageal atresia/stenosis with or without fistula					2.24	1.99	2.06
Small intestine atresia/stenosis					1.71	1.72	1.90
Anorectal atresia/stenosis					4.44	4.85	4.93
Undescended testis (36 weeks of gestation or later)					7.83	9.19	12.23
Hypospadias					18.25	16.57	15.86
Epispadias					0.58	0.70	0.88
Indeterminate sex					1.68	1.00	0.74
Renal agenesis					2.14	1.96	1.93
Cystic kidney					4.32	4.75	5.76
Bladder exstrophy					0.18	0.26	0.14
Polydactyly, preaxial					2.82	3.27	3.84
Total Limb reduction defects (include unspecified)					5.50	5.30	5.54
Transverse					2.59	2.71	2.88
Preaxial					1.14	1.07	1.23
Postaxial					0.26	0.21	0.25
Intercalary					0.10	0.12	0.18
Mixed					1.25	0.95	0.82
Unspecified					0.17	0.23	0.18
Diaphragmatic hernia					2.70	2.63	2.85
Omphalocele					2.29	2.14	2.02
Gastroschisis					3.77	4.16	5.76
Unspecified Omphalocele/Gastroschisis					0.62	0.64	0.51
Prune belly sequence					0.26	0.31	0.26
Trisomy 13					1.18	1.20	1.12
Trisomy 18					2.46	2.23	2.69
Down syndrome, all ages (include age unknown)					11.93	12.80	13.36
<20					7.63	7.08	7.64
20-24					6.87	6.53	6.64
25-29					6.44	7.48	7.42
30-34					12.30	12.11	13.21
35-39					35.50	36.57	35.92
40-44					108.22	121.40	113.07
45+					116.86	195.84	187.69
unknown					---	---	---

* data include less than 5 years

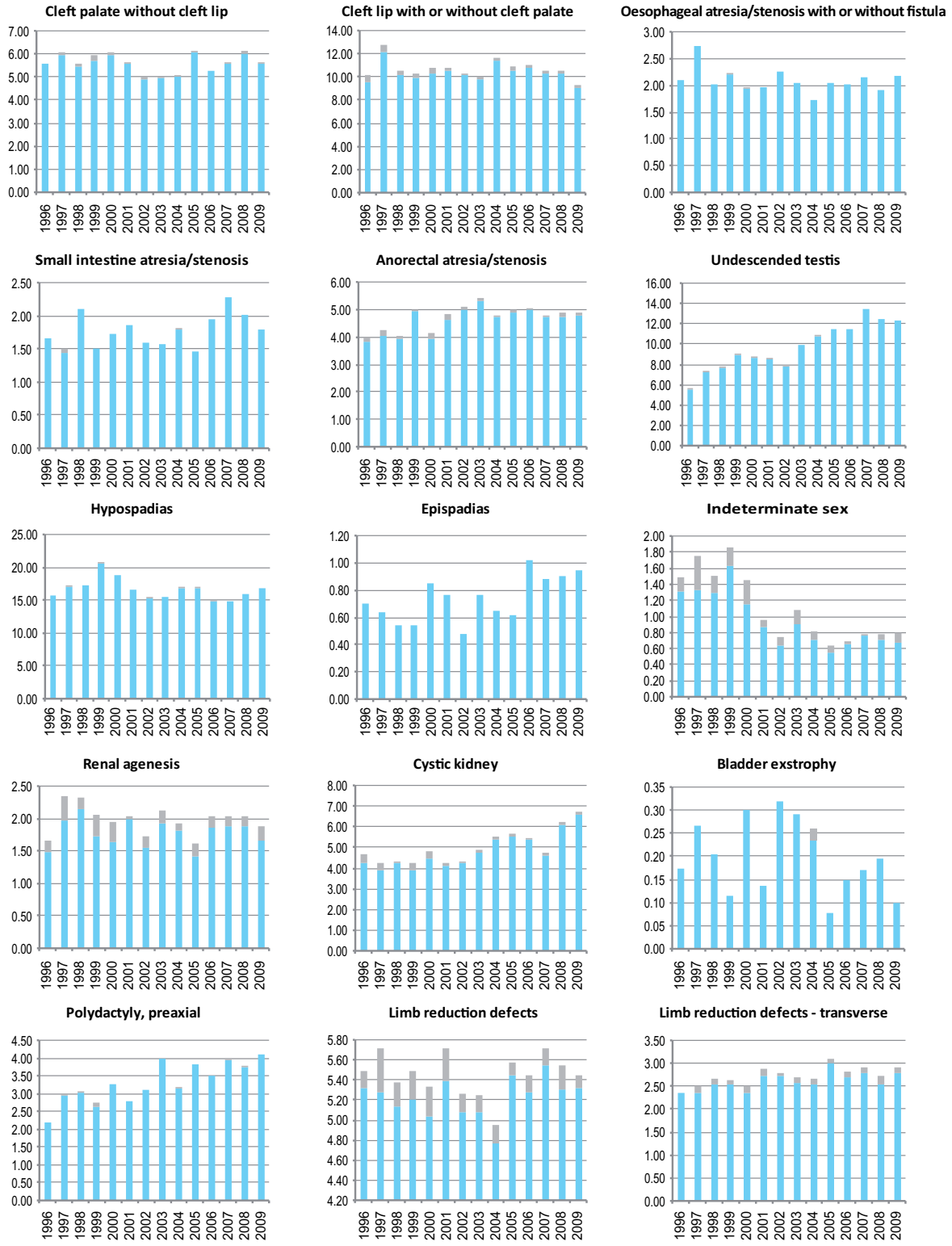
USA-Texas: BDES

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



Note: L+S rates, ToP rates

USA-Texas: BDES



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 Maternal Child Health. 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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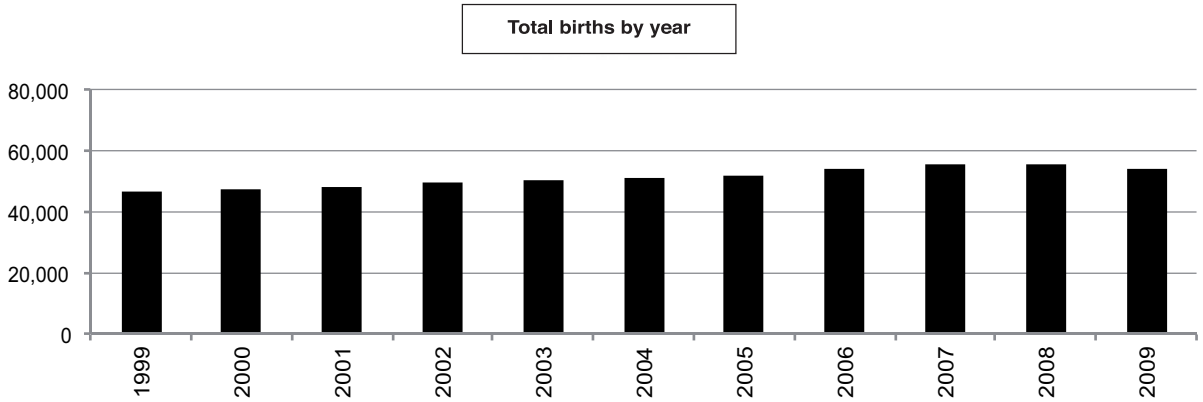
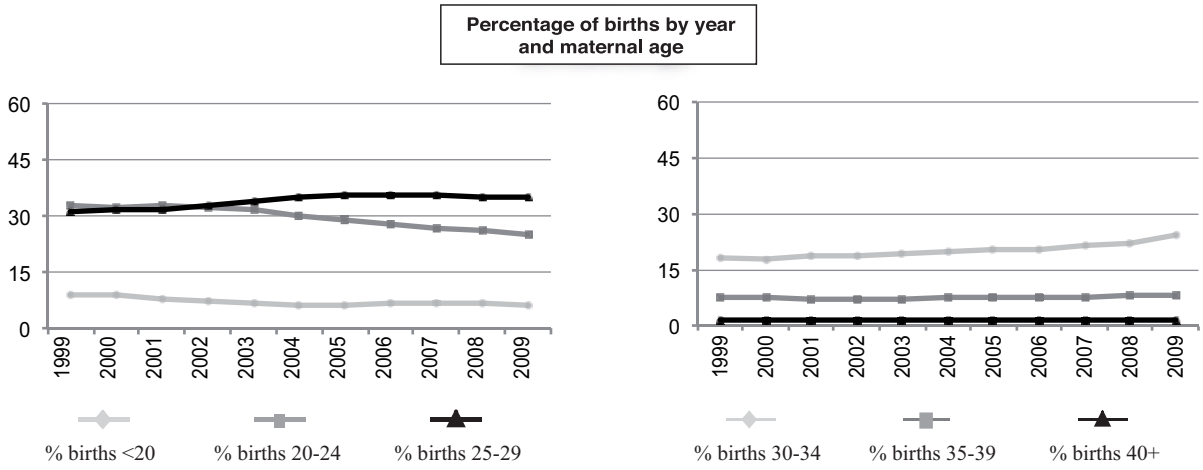
USA-Utah: UBDN





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

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	20	46.5	Cystic kidney	8	11.8
Spina bifida	5	7.4	Limb reduction defects	5	4.8
Encephalocele	6	40.0	Diaphragmatic hernia	1	1.7
Holoprosencephaly	9	24.3	Omphalocele	10	20.4
Hydrocephaly	2	4.0	Gastroschisis	2	2.3
Hypoplastic left heart syndrome	3	4.8	Trisomy 13	8	25.0
Cleft palate without cleft lip	2	2.0	Trisomy 18	18	32.7
Cleft lip with or without cleft palate	9	4.1	Down syndrome	27	11.3
Renal agenesis	4	8.5			

Total ToPs with births defects = 136 (Ratio ToPs/Births: 0.82 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Utah: UBDN, 2009

Live births (LB)	53,849
Stillbirths (SB)	297
Total births	54,146
Number of terminations of pregnancy (ToP) for birth defects	49

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	4	10	2.95
Spina bifida	17	1	0	3.32
Encephalocele	3	0	2	0.92
Microcephaly	32	0	0	5.91
Holoprosencephaly	9	1	3	2.40
Hydrocephaly	4	0	0	0.74
Anophthalmos	3	1	0	0.74
Microphthalmos	6	0	0	1.11
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	0	0	0	0.00
Microtia	17	0	1	3.32
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	12	2	0	2.59
Tetralogy of Fallot	14	1	1	2.95
Hypoplastic left heart syndrome	19	1	1	3.88
Coarctation of aorta	43	2	2	8.68
Choanal atresia, bilateral	5	0	0	0.92
Cleft palate without cleft lip	30	0	0	5.54
Cleft lip with or without cleft palate	74	0	4	14.41
Oesophageal atresia/stenosis with or without fistula	14	0	1	2.77
Small intestine atresia/stenosis	5	0	0	0.92
Anorectal atresia/stenosis	18	0	2	3.69
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	58	0	0	10.71
Epispadias	1	0	0	0.18
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	13	1	1	2.77
Cystic kidney	17	2	6	4.62
Bladder exstrophy	1	0	0	0.18
Polydactyly, preaxial	nr	nr	nr	nr
Total Limb reduction defects (include unspecified)	32	0	0	5.91
Transverse	12	0	0	2.22
Preaxial	8	0	0	1.48
Postaxial	2	0	0	0.37
Intercalary	4	0	0	0.74
Mixed	30	0	0	5.54
Unspecified	2	0	0	0.37
Diaphragmatic hernia	17	1	0	3.32
Omphalocele	14	3	4	3.88
Gastroschisis	20	2	1	4.25
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	2	1	2	0.92
Trisomy 13	8	1	4	2.40
Trisomy 18	7	5	5	3.14
Down syndrome, all ages (include age unknown)	69	4	15	16.25
<20	3	1	0	11.82
20-24	8	0	0	5.96
25-29	9	1	0	5.32
30-34	16	0	5	16.23
35-39	18	2	6	57.97
40-44	12	0	4	208.33
45+	3	0	0	476.19
unknown	0	0	0	---

nr = not reported

USA-Utah: UBDN, Previous years rates 1999 - 2009

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

	1974-1979	1980-1984	1985-1989	1990-1994	1995-1999*	2000-2004	2005-2009
Total births					**46,458**	**246,111**	**270,568**
Anencephaly					1.94	2.07	2.70
Spina bifida					3.44	3.94	4.21
Encephalocele					0.22	0.98	0.92
Microcephaly					3.01	4.75	5.21
Holoprosencephaly					1.08	1.34	2.14
Hydrocephaly					3.01	4.71	3.40
Anophthalmos					0.00	0.24	0.52
Microphthalmos					1.94	1.50	1.55
Unspecified Anophthalmos/Microphthalmos					0.00	0.00	0.00*
Anotia					0.22	0.08	0.15
Microtia					1.08	2.76	3.14
Unspecified Anotia/Microtia					0.00	0.00	0.00*
Transposition of great vessels					6.46	4.96	3.95
Tetralogy of Fallot					6.24	3.90	3.44
Hypoplastic left heart syndrome					3.87	3.58	3.59
Coarctation of aorta					8.83	7.88	9.13
Choanal atresia, bilateral					0.00	0.16	0.44
Cleft palate without cleft lip					6.03	7.72	6.50
Cleft lip with or without cleft palate					12.70	14.38	13.05
Oesophageal atresia/stenosis with or without fistula					4.30	2.19	2.96
Small intestine atresia/stenosis					1.72	1.06	1.59
Anorectal atresia/stenosis					4.52	3.17	3.47
Undescended testis (36 weeks of gestation or later)					nr	nr	nr
Hypospadias					4.09	4.79	9.54
Epispadias					0.43	0.16	0.07
Indeterminate sex					nr	nr	nr
Renal agenesis					4.30	3.45	3.22
Cystic kidney					3.01	5.85	4.51
Bladder exstrophy					0.22	0.20	0.15
Polydactyly, preaxial					nr	nr	nr
Total Limb reduction defects (include unspecified)					6.03	5.81	6.69
Transverse					4.09	2.72	3.47
Preaxial					0.86	1.79	1.37
Postaxial					0.00	0.12	0.22
Intercalary					0.00	0.12	0.30
Mixed					0.65	0.93	1.77
Unspecified					0.22	0.16	0.26
Diaphragmatic hernia					2.58	3.66	3.33
Omphalocele					2.15	2.84	2.81
Gastroschisis					4.30	4.84	5.21
Unspecified Omphalocele/Gastroschisis					0.00	0.00	0.00*
Prune belly sequence					0.00	0.20	0.26
Trisomy 13					0.65	1.71	2.11
Trisomy 18					3.66	3.33	3.51
Down syndrome, all ages (include age unknown)					15.93	15.60	14.38
<20					6.96	11.41	8.44
20-24					7.89	8.82	7.55
25-29					11.08	8.37	8.26
30-34					9.54	15.70	12.42
35-39					76.54	46.37	46.29
40-44					109.38	161.20	160.79
45+					185.19	526.32	276.68
unknown					---	---	---

nr = not reported
* data include less than 5 years

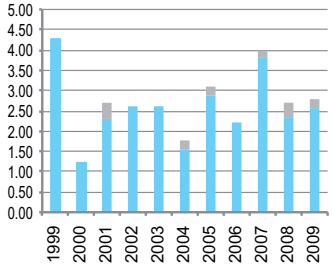
USA-Utah: UBDN

Time trends 1999-2009 (Birth prevalence rates per 10,000)

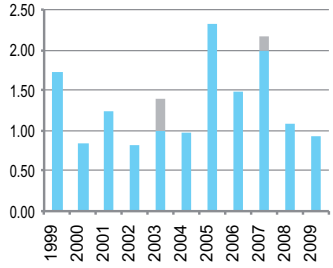
Note: L+S rates, ToP rates

USA-Utah: UBDN

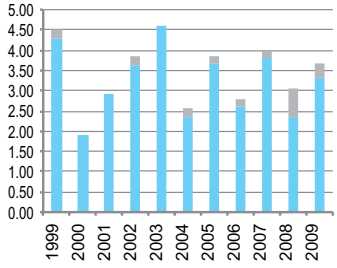
Oesophageal atresia/stenosis with or without fistula



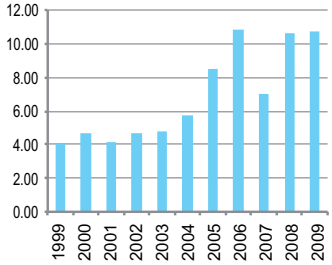
Small intestine atresia/stenosis



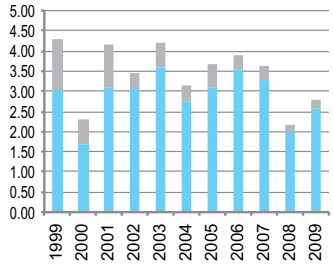
Anorectal atresia/stenosis



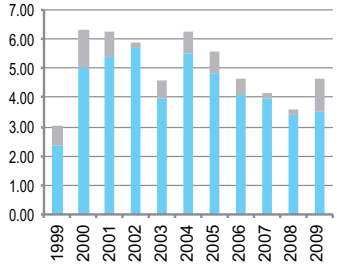
Hypospadias



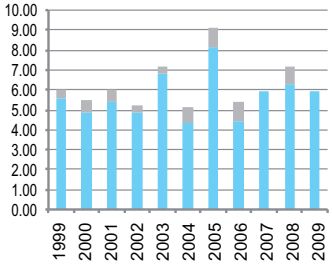
Renal agenesis



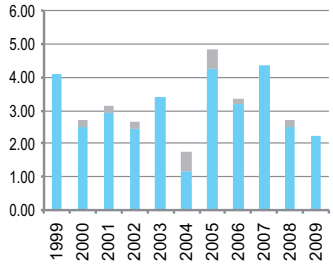
Cystic kidney



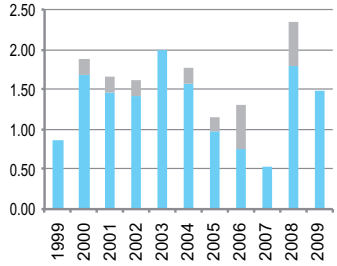
Limb reduction defects



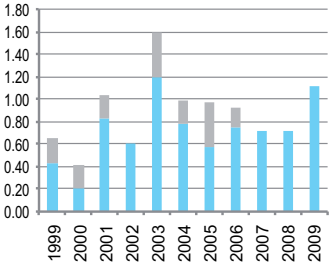
Limb reduction defects - transverse



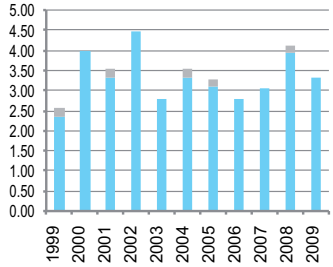
Limb reduction defects - preaxial



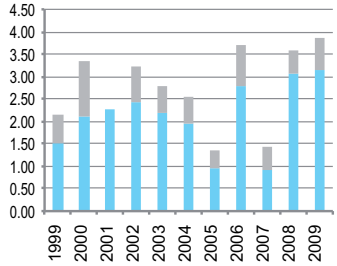
Limb reduction defects - mixed



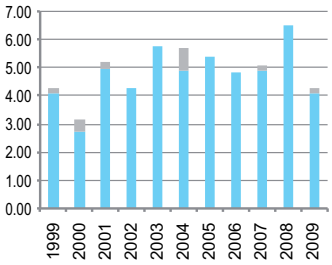
Diaphragmatic hernia



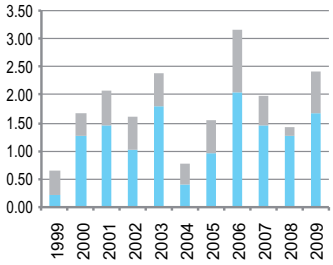
Omphalocele



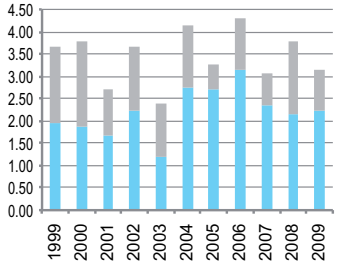
Gastroschisis



Trisomy 13

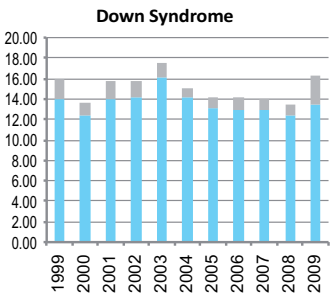


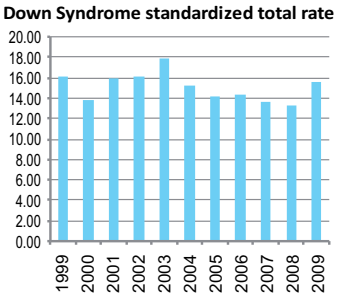
Trisomy 18



Note: L+S rates, ToP rates

USA-Utah: UBDN





Note: L+S rates, ToP rates

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

Australia: VBDR
Victorian Birth Defects Registry

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

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

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

Sources of ascertainment:
Perinatal forms (approx 48.8%)
Hospital listings* (aPprox 28.8%)
Perinatal death certificates/autopsy reports (approx 7.8%)
Cytogenetic reports (approx 9.3%)
Maternal & Child Health Nurse (approx 4.2%)
Other professionals/parents (approx 1.1%)

* These include obtaining annual inpatient listings from the two major paediatric teaching hospitals detailing all children up to the age of five years who have been subsequently admitted to these hospitals each year with a birth defect. We also obtain annual listings from specialist clinics at these hospital for all children up to the age of five years who have visited either as an inpatient or an outpatient. This procedure has also been adopted for Monash Medical Centre. Other listings are also received from Newborn Screening Services and Genetic Health Services Victoria.

Exposure information:
No exposure information is available.

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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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United Kingdom-Wessex: WANDA

Wessex Antenatally Detected Anomalies Register

History:
The Registry was formally established in 1994, and is located in the Clinical Genetics Department of the teaching hospital in Southampton. The focus of the register is antenatal and includes all fetuses suspected to have a congenital anomaly. All babies born with an anomaly, potentially detectable antenatally, are also included. There is no limit to the age at which cases may be reported, but in reality few cases are registered after the neonatal period. The link with Genetics, however, ensures the inclusion of all unbalanced chromosome errors, whenever detected. The term 'congenital anomaly' is used here in its widest sense and includes chromosome errors, inborn errors of metabolism and syndromes where a gene mutation has been identified.
With the clinical perspective to this register, multidisciplinary meetings are held on a regular basis in each district covered. At these, all cases that have arisen in the intervening time period are discussed and management issues addressed. In addition, feedback from the register is used to inform local policies.

Size and coverage:
The Register is population based with approximately 27,000 deliveries per year and covers all births in the old Wessex region, Jersey and Guernsey. All miscarriages, stillbirths, TOPFAs and live births are included where an anomaly has been diagnosed.

Sources of Ascertainment:
Reporting is voluntary and multisource and includes sonographers, radiologists, obstetricians, midwives, paediatricians, paediatric surgeons, paediatric cardiologists, geneticists, genetics laboratories and pathologists.

Exposure information:
This is anecdotally recorded only.

Background information:
The approach of the register is to focus on collecting data that is reliably available and so relatively complete. This includes maternal and child demographics, full antenatal findings, test results and the postnatal findings and diagnosis. This may include family history and maternal health and medications but data on the father are not kept unless relevant to the diagnosis of the fetus/child.

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USA-California: CBDMP
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.

Collaborative Publications

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

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Annual Report 2011

with data for **2009**

Published by
The Centre of the International Clearinghouse for Birth Defects Surveillance and Research