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with data for 2008

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

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INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH
ANNUAL REPORT 2010 (WITH DATA FOR 2008)

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Collaborative Research Projects

Multiple Congenital Anomalies (MCA), 2008

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

Introduction

For the year 2008, we received data from 8 programmes, for a total of 2721 reported cases, among 486,632 births (Table 1). Of these, 674 were reported as syndromes and 988 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 Lopez-Camelo.

Main findings and comments

This year, among the 47 defect groups, 40 were associated with an O/E ratio greater than 1. Seven 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 3 two-defect (Table 3) and for 1 three-defect combinations (Table 4).
For all comparisons, the data reported from 1992 through 2006, over 5,756,157 births were used as baseline.

Table 1: Cases of MCA, by programme and number of defects (2008).

PROGRAMME	Births	Total cases Reported	Known etiology (syndromes)	< 2 major unrelated defects	2 Or +	Rate
Canada-British Columbia	44580	272	40	153	79	17.72
Finland	59719	397	199	55	143	23.93
Israel	41998	30	0	5	25	5.95
Japan	85855	665	241	264	160	18.64
Mexico	22459	38	11	3	24	10.69
South America	138307	1084	110	561	413	29.86
Usa Atlanta	54899	96	28	4	64	11.65
Wales (*)	38815	139	45	14	80	20.61
TOTAL	486632	2721	674	1059	988	20.37

(*) Data provided from 2008, not monitored due to lacking baseline frequencies

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

Defect group	N	Expected	Rate ratio	Excess	Poisson
Congenital heart defects	397	255.6	1.55	141.4	***
Other urinary tract defects	124	88.2	1.41	35.9	***
Cleft lip+/palate	111	79.4	1.40	31.6	***
Other brain defects	81	50.5	1.60	30.5	***
Deformations	120	93.9	1.28	26.1	
Polydactyly	88	63.9	1.38	24.1	***
A/polysplenia	31	7.6	4.11	23.5	***
Hydrocephaly	80	58.4	1.37	21.7	
Limb reduction defects, other types	42	22.2	1.89	19.8	***
Omphalocele	56	38.2	1.47	17.8	
Anorectal atresia	102	86.2	1.18	15.8	
Diaphragmatic hernia	42	27.5	1.53	14.5	
Renal a/dysgenesis	49	35.8	1.37	13.2	
An-microphthalmia	37	24.0	1.54	13	
Other severe craniofacial defects	27	15.7	1.72	11.3	
Other eye anomalies	30	19.9	1.51	10.1	
Encephalocele	24	14.4	1.67	9.6	
Severe genitalia defects	48	38.6	1.24	9.4	
Spina bifida	35	26.5	1.32	8.6	
Syndactyly	31	22.8	1.36	8.2	
Cystic kidney	31	23.2	1.34	7.8	
Anencephaly	19	11.8	1.62	7.3	
Other ear anomalies	16	9.2	1.74	6.8	
Other small intestinal atresias	15	8.6	1.75	6.4	
Microcephaly	35	28.9	1.21	6.1	
Neck anomalies	12	6.1	1.98	5.9	
Esophageal atresia	60	54.7	1.10	5.3	
Transverse limb reduction defects	21	16.0	1.32	5.1	
Gastroschisis	17	12.5	1.36	4.5	
Hypospadias	42	37.6	1.12	4.4	
Sacrum anomalies	6	2.7	2.26	3.4	
Holoprosencephaly	13	10.9	1.19	2.1	
Other rare defects (Teratoma, sirenomelia)	6	4.1	1.48	2	
Duodenal atresia	14	12.3	1.14	1.7	
Cleft palate	57	55.6	1.02	1.4	
Other intestinal anomalies	24	22.7	1.06	1.3	
Bladder exstrophy	7	5.9	1.18	1.1	
Vessel anomalies	3	2.6	1.17	0.4	
Craniostenosis	6	5.8	1.04	0.2	
Broncho-pulmonary defects	25	24.8	1.01	0.2	
Gut malrotation	7	7.3	0.96	-0.3	
Laryngeo-tracheal defects	3	4.4	0.69	-1.4	
Choanal atresia	4	6.2	0.64	-2.2	
Axial skeleton defects	56	60.4	0.93	-4.4	
Anotia/microtia	34	40.3	0.84	-6.3	
Preaxial limb reduction defects	14	21.9	0.64	-7.9	

***= p<0.001

Table 3: Significant two-defect combinations.

Malformation-1	Malformation-2	N	Exp	Rate Ratio	Excess
Spina bifida	Spleen anomalies	3	0.08	37.5	2.9
Anorectal atresia	Other gut atresias	7	0.86	8.1	6.1
Congenital heart defects	Spleen anomalies	24	5.68	4.2	18.3

Table 4: Significant Three-defects combinations.

Malformation-1	Malformation-2	Malformation-3	N	Exp	Rate Ratio	Excess
Other intestinal anomalies	omphalocele	genitalia defects	3	0.08	37.5	2.9

Comments:

Significant 2-defects associations:

No outstanding common pattern could be observed, except for other laterality defects for the combinations involving spleen anomalies.
In one of the 3 cases combining spina bifida and spleen anomalies (FIN 20080107, 20080362, 20081033) an OEIS association was suspected (the same case can be found below as a significant 3-defect association).

Significant 3-defect association:

All 3 cases combining other intestinal anomalies, omphalocele and genitalia defects suggested an OEIS association (FIN 20080107, 20081617, 20081726).

Furthermore, and according to the definitions, the following cases potentially exposed to the three monitored teratogens were detected:

Rubella: 11 cases:

SAM G1120308: Microcephaly, septal defect.

SAM A0525908: Anophthalmia, complex heart defect.

(the remaining 9 were already reported in the 2008 quarterly reports).

Retinoic acid: 1 case:

USA 69: Hydrocephaly; bilateral cleft lip and palate; small ear canals bilaterally; left ear tag and pit; mild left pelviectasis; inferior pole mass on left kidney; PFO; PDA; perimembraneous VSD with inlet extension; absence of septum pellucidum; corpus callosum not identified; cerebellum not identified.

Thalidomide: 4 cases

(all 4 were already reported in the 2008 quarterly reports).

Prenatal Diagnosis and Down Syndrome, 2008

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 (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.

2008 Data

During 2008, 22 programmes (Hungary, Iran and Italy:Lombardy joined the survey for the first time) providing data (Table 1) on 2957 DS cases, 1318 of them (44.6%) terminated on the basis of prenatal diagnoses. The total number of births under surveillance in the 22 programmes was 1,562,133.

The percentage of terminations of pregnancy (ToP) (Table 2) ranged from the lowest values in USA:Texas (3.2%), Iran (7.4%), and USA:Atlanta (11.0%), to the highest –as in the previous years- in the registries of Czech Republic (83.3%) and French and Italian programs. The French registries show percentages of ToP that ranged from 78.9% of REMERA to 76.4% of Paris, with a mean value of 77.9%. For the 3 Italian registries the percentages of terminations range from the highest of MER (71.4%), Tuscany (65.5%) to the lowest of Lombardy (36.4%) with a mean value of 66.7%.

In the European registries that provided a data set of 16 years (1993-2008), 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 (2006, 2007 and 2008) respectively 65.4%, 67.6% and 73.3% (611/833).

The comparison of the percentages of ToPs in 2008, in all the 14 West European Countries (59%, 947/1604) and the extra-European Countries (Australia:VBDR, Canada:Alberta, Cuba, and the two USA registries: Atlanta and Texas) (21.1%, 214/1013) is significantly different (c2 = 360 p<.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 2008 it is over 20% (Israel:IBDMS 20.8%, Sweden 21.8%, Australia:VBDR 26.6%, France:Paris 29.6% and all the three Italian Registries (IMER, Lombardy and Tuscany) show the highest values: 30.8%, 32.2% and 33% respectively .

The higher percentage of terminations are frequently detected in the registries that show the highest percentages of higher aged mothers. In fact overall, the proportion of DS pregnancies which were terminated among women at higher risk (³35 years old), was very high in the two France Registries (Paris:72.7% and REMERA:82.5%); in two of the Italian (IMER: 68.9% and Tuscany: 69.8%) where we observe the higher percentage of mothers over 35 years old. There are anyway some exceptions to this consideration and this is observed in the Czech Registry where in spite of a very high percentage of ToPs (91.9%) in mothers aged ≥35 years we observe a very low percentage (12.3%) of mother of the same group. The same consideration could be made for Germany:Saxony-Anhalt where the percentage of ToPs is very high (81.3%) despite the low percentage of mothers aged ≥35 years. Percentages of ToPs less than 20% were observed in three registries: the two of the USA: Texas and Atlanta (4%, and 17.7% respectively), and Iran (9.1%) (Table 3).

In 2008 the most common technique, used for prenatal diagnosis, was AC (Table 4), with a mean value of 59.4%. CVS, with a mean value of 40.1%, showed a progressive significant increase in the years (p: <0.0001): 18.3% in 1995, 19.0% in 1996, 19.3% in 1997, 18.2% in 1998, 20.2% in 1999, 21.8% in 2000, 22.9% in 2001, 28.6% in 2002 and in 2003, 30% in 2004, 35% in 2005, 34.7% in 2006, 29.8% in 2007 and 40.1% in 2008.

In the Registries of Northern-Netherland, Australia:VBDR, Canada:Alberta and Finland, CVS is the most used technique of prenatal detection with a rate of 80.7%, 64.7% , 60% and 54.5% 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 (15±2.9), in Australia:VBDR (15.5±2.3) and in Finland (15.8±2.2) (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 15 wks in many Registries, from the lowest in the Czech Republic (12.74±1.1) to the highest in Wales (15.5±2.5) (Table 5).

The prevalence at birth of DS has decreased in the majority of the 13 programmes that can provide the rates for all the 16 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 7.52 in 1993 to 3.67 x 10,000 in 2008), France:REMERA (from 10.98 in 1993 to 5.94 in 2008), Italy:Tuscany (from 11.93 in 1993 to 6.42 in 2008) and Italy:IMER (from 8.97 to 5.66) and Northern-Netherlands (from 9.86 to 7.25) (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 of the prevalence at birth in the years as in Canada:Alberta (from 11.45 in 1993 to 13.46 in 2008) and in USA:Atlanta (from 12.02 in 1993 to 14.75 x 10,000 in 2008) in connection with the generalized 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
AUSTRALIA:VBDR	X	X	X	X	X	X				X	X	X	X	X		X
CANADA: ALBERTA					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
CUBA													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
FRANCE:REMERA	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
FRANCE: STRASB	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
GERM.: Sax.–Anhalt								X	X	X	X	X	X	X	X	X
HUNGARY																X
IRAN																X
ISRAEL: IBDMS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
ITALY: BDRCam	X	X	X	X	X	X	X	X	X	X	X	X	X		X	
ITALY: IMER	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	
ITALY: Tuscany	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
MOSCOW Region											X	X	X	X	X	X
NORWAY															X	X
NORTHERN NETH.	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
SLOVAK												X			X	X
SWEDEN								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
USA: UTAH												X	X	X	X	
WALES												X	X	X	X	X
WESSEX															X	

Table 2. Percentage (%) of terminations (TOP) among the total number of cases recorded in 2008

Monitoring Program	Maternal Age (years)					
	<= 29	30 – 34	35 – 37	38 – 39	>= 40	Total
Australia: VBDR	28.1	45.5	62.5	54.8	53.8	60.8
Canada: Alberta	0	15.7	52.9	33.3	42.3	29.2
Cuba	8.6	19.0	37.5	87.5	65.5	45.6
Czech Republic	75.4	75.9	89.1	100	89.5	83.3
Finland	37.1	44.0	72.4	50.0	77.5	55.4
France: REMERA	81.5	80.6	81.8	81.8	83.3	78.9
France: Paris	75.0	90.5	90.9	70.8	69.0	76.4
Germany: Sax.-Anhalt	60.0	50.0	100	66.7	85.7	67.6
Hungary	30.2	34.5	51.8	94.7	78.3	45.2
Iran	0	25.0	25.0	0	0	7.4
Israel: IBDMS	0	0	0	40.0	33.3	15.0
Italy: IMER	50.0	94.9	54.5	90.0	85.7	71.4
Italy: Lombardy	0	50.0	0	100	20.0	36.4
Italy: Tuscany	83.3	28.6	55.6	75.0	72.7	65.5
Moscow Region	20.9	8.0	21.9		23.1	18.4
Norway	16.7	42.9	36.4		58.6	38.7
Northern Netherlands	25.0	54.5	42.9	100	66.7	53.6
Slovak	10.5	33.3	55.6	50.0	16.7	30.6
Sweden	21.1	44.0	68.5	70.5	75.0	57.3
USA: Atlanta	0	7.4	23.5	18.2	11.8	11.0
USA: Texas	2.4	2.8	7.4	0	3.5	3.2
Wales	25.0	29.4	69.2	33.3	44.4	39.1

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 (* 10,000)	
	aged >=35	aged >=35	L+S	L+S+ToP
Australia: VBDR	26.6	57.3	24.4	57.2
Canada: Alberta	15.7	43.1	37.9	73.2
Cuba	-	-	65.9	-
Czech Republic	12.3	91.9	6.8	83.8
Finland	18.2	67.7	29.4	90.8
France: REMERA	19.1	82.5	15.1	86.4
France: Paris	29.6	72.7	26.7	98.0
Germany: Saxony-Anhalt	13.9	81.3	12.2	65.0
Hungary	13.6	72.5	14.0	51.0
Iran	8.8	9.1	52.6	57.9
Israel: IBDMS	20.8	27.3	18.4	25.2
Italy: IMER	30.8	68.9	13.8	44.4
Italy: Lombardy	32.2	33.3	32.3	48.4
Italy: Tuscany	33.0	69.8	12.6	41.8
Moscow Region	8.9	22.2	62.5	80.3
Norway	19.4	45.2	33.4	60.9
Northern Netherlands	19.2	61.5	14.5	37.8
Slovak	-	44.0	-	-
Sweden	21.8	71.4	23.6	82.5
USA: Atlanta	17.6	17.7	38.4	46.6
USA: Texas	11.7	4.0	44.8	46.7
Wales	16.9	51.6	24.7	51.1

Table 4 . Down Syndrome techniques of prenatal diagnosis (number of cases) registered in 2008 grouped in maternal age classes.

Monitoring Program	<35				35-39				>39				Tot*			
	CVS	AC	CC	UK	CVS	AC	CC	UK	CVS	AC	CC	UK	CVS	AC	CC	UK
Australia: VBDR	14	10	-	-	21	20	-	1	12	8	-	1	90	49	-	2
Canada : Alberta	3	-	-	-	5	7	-	2	7	3	-	1	15	10	-	3
Cuba	-	7	-	-	-	37	-	-	-	19	-	-	-	68	-	-
Czech Republic	31	-	75	-	-	21	59	-	-	16	18	-	68	152	-	-
Finland	18	14	-	3	17	19	-	-	19	12	-	-	54	45	-	3
France : REMERA	20	31	-	-	11	32	-	2	11	23	-	1	42	86	-	3
France : Paris	10	15	-	-	11	16	-	-	14	15		-	35	46	-	-
Germany:Sax-Anha	10	-	-	-	7	-	-	-	6	-	-	-	23	-	-	-
Hungary	-	-	-	33	-	-	-	32	-	-	-	18	-	-	-	84
Iran	-	-	-	1	-	-	-	1	-	-	-	-	-	-	-	2
Israel: IBDMS	-	-	-	-	-	2	-	-	-	4	-	-	-	6	-	-
Italy: IMER	8	9	-	-	16	12	-	-	4	8	-	-	28	32	-	-
Italy: Lombardy	-	-	-	1	-	-	-	2	-	-	-	1	-	-	-	4
Italy Tuscany	4	3	-	-	1	12	-	1	3	9	-	1	9	24	-	2
Moscow Region	5	5	1	-	1	2	4	-	2	1	-	-	8	8	5	-
Northern Netherl.	6	1	-	-	5	1	-	-	2	-	-	-	13	2	-	-
Sweden	15	27	-	3	17	49	-	15	13	28	-	13	45	104	-	31
USA : Atlanta	1	1	-	-	1	5	-	-	1	-	-	1	3	6	-	1
Wales	4	4	-	1	3	8	-	1	1	3	-	-	8	15	-	2
Total	**149**	**127**	**76**	**42**	**116**	**243**	**63**	**57**	**95**	**150**	**18**	**37**	**441**	**653**	**5**	**138**

CVS = Chorion Villus sampling
AC = Amniocentesis
CC = Chordocentesis
UK = Unknown
*+casi con età materna non nota

Table 5. Mean gestational age (weeks) and Standard Deviation of induced abortions by maternal age group and by type of prenatal diagnosis.

Monitoring Program	<=34			>=35		
	CVS	AC	Total	CVS	AC	Total
Australia: VBDR	13.54±1.61	17.33±2.29	15.09±2.67	14.03±1.66	17.11±1.83	15.47±2.32
Canada: Alberta	13.33±1.15	-	13.33±1.15	15.33±1.30	19.30±1.25	17.14±2.38
Czech Republic	12.74±1.09	18.64±3.15	16.92±3.82	13.00±1.20	17.94±2.17	16.33±3.00
Finland	13.94±1.11	18.43±2.38	15.91±2.86	14.22±1.48	17.55±1.55	15.76±2.24
France: REMERA	14.15±1.79	21.45±4.06	18.59±4.91	14.86±1.67	21.55±4.03	19.64±4.64
France Paris	14.20±1.48	21.47±3.02	18.56±4.40	13.64±1.32	19.52±2.77	16.89±3.69
Germany:Sax-Anha	-	17.90±1.73	17.90±1.73	-	18.38±1.80	18.38±1.80
Israel: IBDMS	-	-	-	-	24.50±2.81	24.50±1.81
Italy: IMER	15.14±2.73	19.00±1.85	17.20±2.98	14.30±2.03	18.75±2.02	16.52±3.01
Italy: Tuscany	14.00±1.41	19.33±1.15	16.29±3.09	13.75±0.50	18.86±1.77	18.04±2.51
Moscow Region	12.00±0.00	19.40±2.19	15.70±4.16	12.00±0.00	18.67±1.15	15.33±3.72
Northern Netherlan.	13.50±1.22	23.00±0.00	14.86±3.76	14.00±1.41	21.00±0.00	15.0±2.94
USA: Atlanta	14.00±0.00	23.00±0.00	18.50±6.36	20.00±5.66	18.75±2.50	19.17±3.25
Wales	15.50±2.52	19.25±1.89	17.38±2.88	13.50±0.58	16.55±1.63	15.73±1.98

Table 6. Prevalence at birth (x 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
Australia: VBDR										12.5	8.49	11.03	10.85	11.45		12.57
Canada: Alberta	11.45	11.07	13.15	8.49	11.14	14.02	11.56	14.65	15.2	12.71	19.2	16.52	20.54	13.43	16.42	13.46
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
Cuba													8.31	8.72		7.33
England & Wales	4.59	4.73	4.91	5.50	6.39	7.18	6.71	6.60	6.27	5.9		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
France CE/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
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
France: Strasbourg	16.75	17.87	24.04	17.44	27.95	2.20	4.34	5.62	2.23	2.96	5.18	8.2	5.81	7.17	8.54	
Germany: Saxony Anh.	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	10.0	8.01	6.19
Hungary																10.24
Iran																11.52
Israel: IBDMS	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
Italy: BDRCam	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	
Italy: IMER	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
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	
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
Moscow region												10.66	13.64	12.11	10.97	14.84
Norway															12.41	10.98
Northern Netherlands	9.86	5.74	9.38	13.74	11.91	10.03	8.43	6.35	9.32	13.31	5.99	9.4	11.87	8.80	11.31	7.25
Slovak															5.67	7.46
Sweden							14.01	11.01	14.59	13.31	15..47	10.56	12.69		11.89	12.73
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
USA: Utah												14.01	13.19	11.91	12.83	
Wales												11.69	13.12	10.05	10.40	10.88
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 be 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 2010 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 ***Janneke Jentink*** as Author of the high quality, original peer-reviewed article "Valproic Acid Monotherapy in Pregnancy and Major Congenital Malformations" published in the New England Journal of Medicine,

Valproic acid monotherapy in pregnancy and major congenital malformations.

Jentink J, Loane MA, Dolk H, Barisic I, Garne E, Morris JK, de Jong-van den Berg LT; EUROCAT Antiepileptic Study Working Group.

Department of Pharmacoepidemiology and Pharmacoeconomics, Division of Pharmacy, University of Groningen, Groningen, the Netherlands.

Comment in: N Engl J Med. 2010 Oct 28;363(18):1771; author reply 1771-2.

Abstract
Background: The use of valproic acid in the first trimester of pregnancy is associated with an increased risk of spina bifida, but data on the risks of other congenital malformations are limited.

Methods: We first combined data from eight published cohort studies (1565 pregnancies in which the women were exposed to valproic acid, among which 118 major malformations were observed) and identified 14 malformations that were significantly more common among the offspring of women who had received valproic acid during the first trimester. We then assessed the associations between use of valproic acid during the first trimester and these 14 malformations by performing a case-control study with the use of the European Surveillance of Congenital Anomalies (EUROCAT) antiepileptic-study database, which is derived from population-based congenital-anomaly registries. Registrations (i.e., pregnancy outcomes with malformations included in EUROCAT) with any of these 14 malformations were compared with two control groups, one consisting of infants with malformations not previously linked to valproic acid use (control group 1), and one consisting of infants with chromosomal abnormalities (control group 2). The data set included 98,075 live births, stillbirths, or terminations with malformations among 3.8 million births in 14 European countries from 1995 through 2005.

Results: Exposure to valproic acid monotherapy was recorded for a total of 180 registrations, with 122 registrations in the case group, 45 in control group 1, and 13 in control group 2. As compared with no use of an antiepileptic drug during the first trimester (control group 1), use of valproic acid monotherapy was associated with significantly increased risks for 6 of the 14 malformations under consideration; the adjusted odds ratios were as follows: spina bifida, 12.7 (95% confidence interval [CI], 7.7 to 20.7); atrial septal defect, 2.5 (95% CI, 1.4 to 4.4); cleft palate, 5.2 (95% CI, 2.8 to 9.9); hypospadias, 4.8 (95% CI, 2.9 to 8.1); polydactyly, 2.2 (95% CI, 1.0 to 4.5); and craniosynostosis, 6.8 (95% CI, 1.8 to 18.8). Results for exposure to valproic acid were similar to results for exposure to other antiepileptic drugs.

Conclusions:: The use of valproic acid monotherapy in the first trimester was associated with significantly increased risks of several congenital malformations, as compared with no use of antiepileptic drugs or with use of other antiepileptic drugs.

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	1 year	20 weeks or 500 grams	Permitted, Not reported
Chile-Maule: RRMC-SSM	Hospital-based Regional	2003	Hospital discharge	500 grams	Not permitted, Not reported
Costa Rica: CREC	Population-based National	2003	3 days	22 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	1 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
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

Synopsis of Contributing Monitoring Systems

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
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	Up to 15 years	24 weeks	Permitted, Reported
Norway: MBRN	Population-based National	1974	Hospital discharge Lifelong for mortality (from 2002 1 year)	16 weeks (12 weeks from 1999)	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 Ukraine Birth Defects Program (Ukraine: OMNI-Net UBDP)	Population-based Regional	2001	1 year	>= 500 grams	Permitted, Reported only for selected malformations
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	2 years	20 weeks	Permitted, Reported
Wales: CARIS	Population-based Regional	2005	1 year	24 weeks	Permitted, Reported

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

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

(***) 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
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
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 -Wessex: WANDA		2			2		8		11			17	20			25										
USA: Atlanta									12		16															
USA: California																										
USA: Texas						7			11,12		15,16							27								
Wales	1	2			2	7									24	25								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
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

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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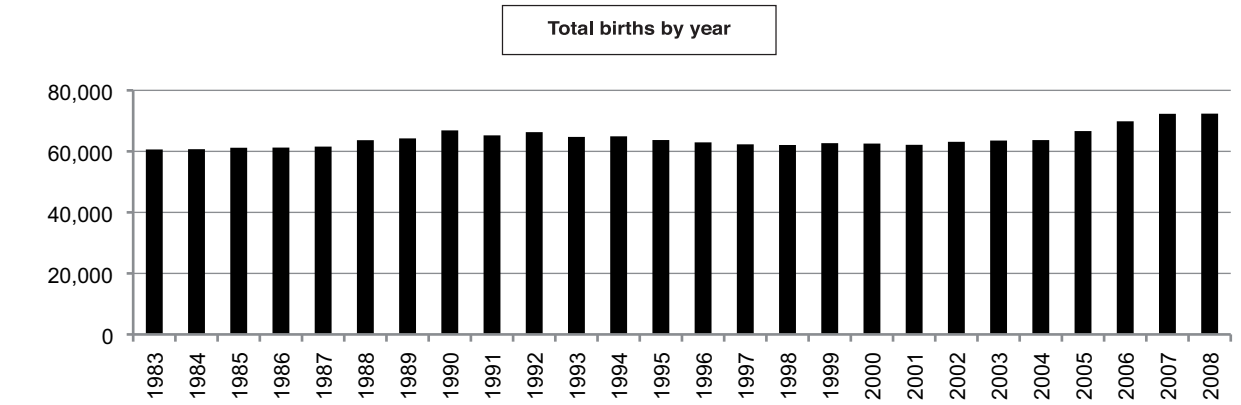
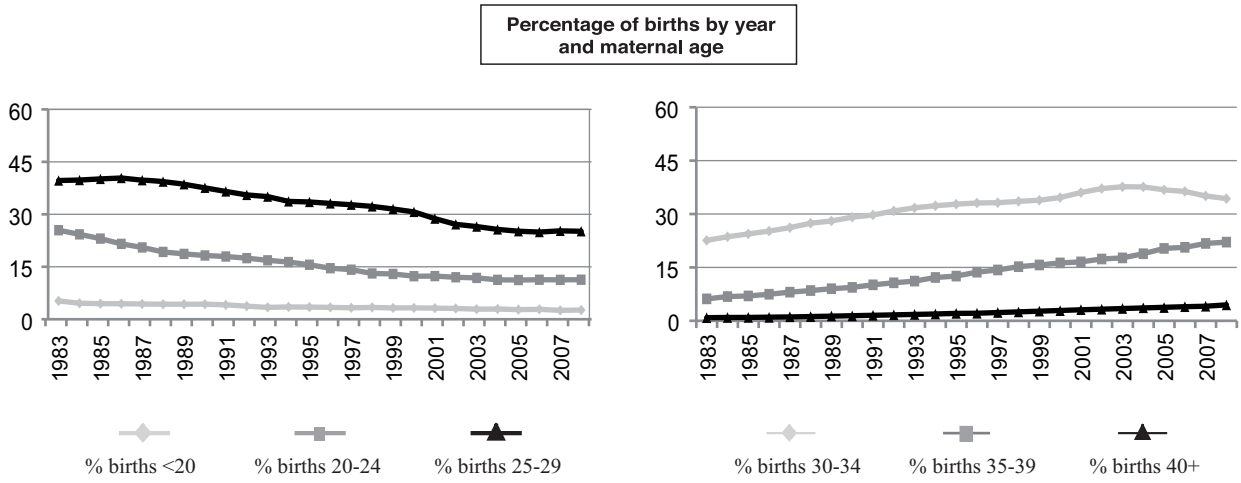
Victorian Birth Defects Register
Victorian Perinatal Data Collection Unit
GPO Box 4003
Melbourne 3001, Australia

Australia: VBDR





Terminations of pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	77	76.2	Cystic kidney	9	7.6
Spina bifida	21	18.9	Limb reduction defects	10	8.0
Encephalocele	6	26.1	Diaphragmatic hernia	4	5.5
Holoprosencephaly	11	55.0	Omphalocele	37	56.1
Hydrocephaly	11	6.4	Gastroschisis	4	9.1
Hypoplastic left heart syndrome	9	10.0	Trisomy 13	50	69.4
Cleft palate without cleft lip	0	0.0	Trisomy 18	153	73.6
Cleft lip with or without cleft palate	18	8.3	Down syndrome	430	62.7
Renal agenesis	2	2.7			

Total ToPs with births defects = 1,083 (Ratio ToPs/Births: 5.05 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: VBDR, 2008

Live births (LB)	71,843
Stillbirths (SB)	524
Total births	72,367
Number of terminations of pregnancy (ToP) for birth defects	359

Birth Defects	Number of cases*			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	<5	5	19	nc
Spina bifida	20	14	<5	nc
Encephalocele	<5	<5	<5	nc
Microcephaly	19	<5	<5	nc
Holoprosencephaly	<5	0	<5	nc
Hydrocephaly	40	16	<5	nc
Anophthalmos	<5	0	0	nc
Microphthalmos	5	<5	0	nc
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	<5	0	0	nc
Microtia	6	0	0	0.83
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	34	7	<5	nc
Tetralogy of Fallot	22	<5	0	nc
Hypoplastic left heart syndrome	24	<5	5	nc
Coarctation of aorta	36	<5	0	nc
Choanal atresia, bilateral	16	0	0	2.21
Cleft palate without cleft lip	47	<5	0	nc
Cleft lip with or without cleft palate	56	<5	9	nc
Oesophageal atresia/stenosis with or without fistula	22	<5	0	nc
Small intestine atresia/stenosis	22	<5	0	nc
Anorectal atresia/stenosis	21	<5	<5	nc
Undescended testis (36 weeks of gestation or later)	358	0	0	49.47
Hypospadias	269	0	0	37.17
Epispadias	<5	0	0	nc
Indeterminate sex	8	<5	0	nc
Renal agenesis	41	7	<5	nc
Cystic kidney	28	7	<5	nc
Bladder exstrophy	<5	0	0	nc
Polydactyly, preaxial	91	6	<5	nc
Total Limb reduction defects (include unspecified)	34	6	5	6.22
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	34	6	5	6.22
Diaphragmatic hernia	19	7	<5	nc
Omphalocele	11	<5	15	nc
Gastroschisis	16	<5	<5	nc
Unspecified Omphalocele/Gastroschisis	27	<5	0	nc
Prune belly sequence	0	0	<5	nc
Trisomy 13	<5	<5	18	nc
Trisomy 18	6	7	70	11.47
Down syndrome, all ages (include age unknown)	79	15	138	32.06
<20	0	0	0	0.00
20-24	6	<5	0	nc
25-29	14	<5	8	nc
30-34	15	<5	15	nc
35-39	28	<5	40	nc
40-44	16	6	21	138.80
45+	0	0	0	0.00
unknown	0	0	54	---

nc = not calculable
nr = not reported
(*) According to national guidelines number of cases < 5 should not be explicitly published

Australia: VBDR, Previous years rates 1983 - 2008

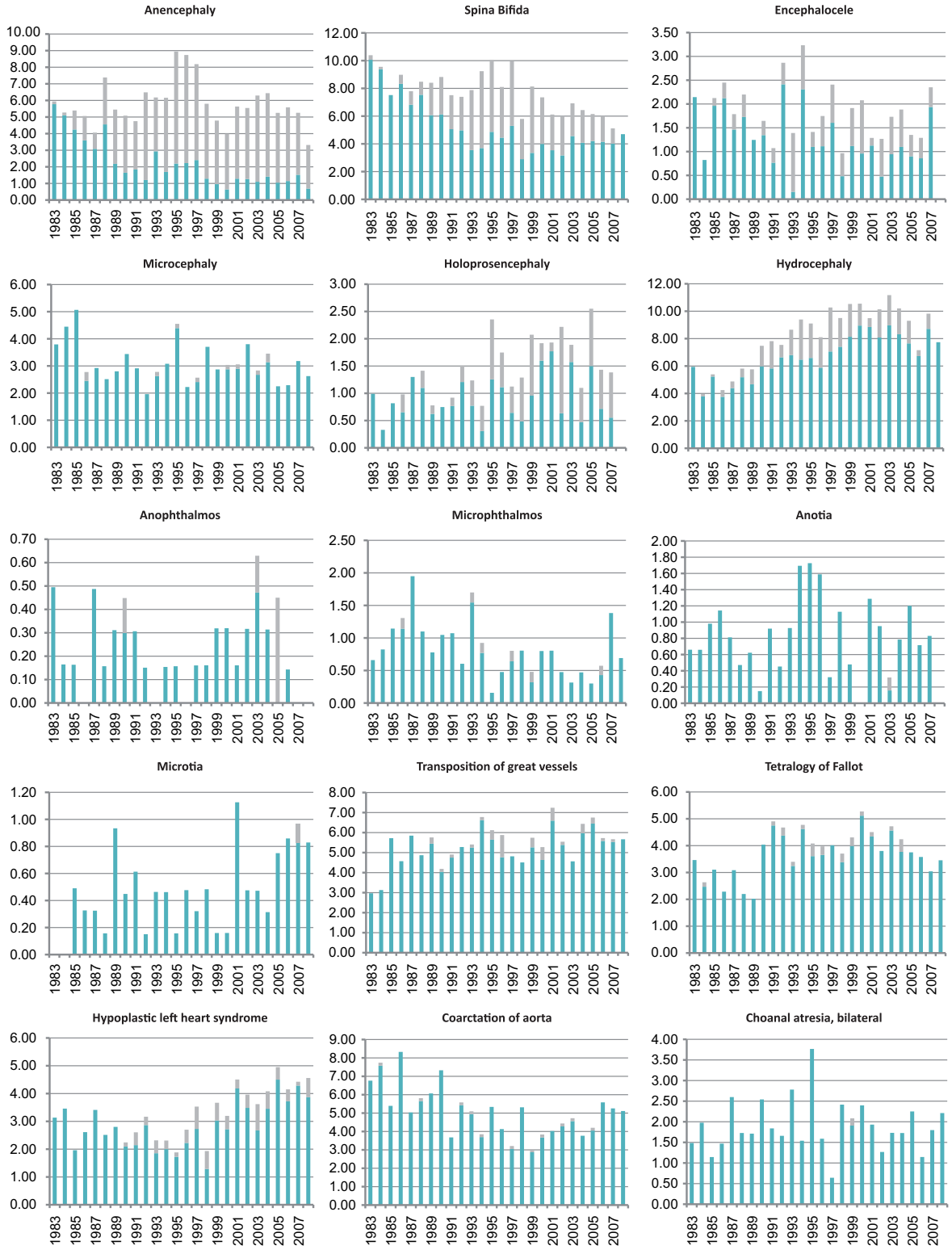
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births		**60,625**	**308,375**	**327,413**	**315,996**	**314,070**	**344,888**
Anencephaly		5.94	5.45	5.59	7.56	5.22	5.20
Spina bifida		10.39	8.46	7.97	8.64	6.91	5.73
Encephalocele		1.65	1.69	1.59	1.80	1.46	1.58
Microcephaly		3.79	3.53	2.78	3.23	3.12	2.90
Holoprosencephaly		0.99	0.97	1.04	1.46	2.01	1.42
Hydrocephaly		5.11	4.41	7.02	8.89	9.97	8.89
Anophthalmos		0.49	0.23	0.24	0.13	0.35	0.25
Microphthalmos		0.66	1.26	1.04	0.63	0.57	0.77
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.66	0.81	0.61	1.30	0.67	0.77
Microtia		0.00	0.26	0.52	0.38	0.48	0.75
Unspecified Anotia / Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		2.97	4.60	5.10	5.63	5.57	6.10
Tetralogy of Fallot		3.46	2.66	3.82	4.11	4.52	3.58
Hypoplastic left heart syndrome		3.13	2.79	2.63	2.47	3.79	4.39
Coarctation of aorta		6.76	6.45	5.59	4.37	4.01	4.86
Choanal atresia, bilateral		1.48	1.78	2.11	1.99	1.88	1.83
Cleft palate without cleft lip		7.92	7.94	6.57	8.10	9.81	7.99
Cleft lip with or without cleft palate		10.72	10.64	10.08	10.13	10.86	10.13
Oesophageal atresia / stenosis with or without fistula		3.30	3.63	3.63	3.99	2.80	3.29
Small intestine atresia / stenosis		0.49	1.13	1.01	1.30	1.78	2.16
Anorectal atresia / stenosis		2.97	3.50	4.09	5.28	3.95	3.80
Undescended testis (36 weeks of gestation or later)		9.57	16.12	39.06	47.18	48.08	55.15
Hypospadias		17.65	18.55	30.24	34.43	35.72	38.45
Epispadias		0.16	0.29	0.37	0.51	0.67	0.62
Indeterminate sex		1.65	1.85	2.90	2.12	1.53	1.55
Renal agenesis		3.30	3.40	2.47	2.63	2.55	2.86
Cystic kidney		2.47	3.21	4.55	6.08	6.46	6.48
Bladder exstrophy		0.66	0.39	0.18	0.47	0.57	0.28
Polydactyly, preaxial		6.76	7.85	9.56	10.41	10.38	13.24
Total Limb reduction defects (include unspecified)		7.09	5.67	6.35	6.93	5.79	6.23
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		7.09	5.67	6.35	6.93	5.79	1.30
Diaphragmatic hernia		2.80	2.98	3.67	4.08	3.28	3.49
Omphalocele		2.14	2.92	3.51	3.58	3.34	3.32
Gastroschisis		0.49	0.88	1.83	2.28	2.64	2.20
Unspecified Omphalocele / Gastroschisis		0.16	0.62	0.58	0.98	0.45	1.09
Prune belly sequence		0.16	0.36	0.27	0.41	0.10	0.19
Trisomy 13		1.15	1.13	1.71	2.31	2.96	3.57
Trisomy 18		1.32	2.63	4.15	6.14	7.23	9.97
Down syndrome, all ages (include age unknown)		11.38	14.46	16.83	20.73	27.86	30.82
<20		6.30	7.33	12.30	5.56	5.10	5.30
20-24		5.83	7.47	9.93	7.92	7.78	9.38
25-29		7.90	8.86	9.75	7.75	10.79	9.70
30-34		13.87	15.59	14.40	15.55	19.44	15.82
35-39		34.81	46.25	43.07	51.10	56.77	54.83
40-44		101.21	114.49	110.29	181.22	188.54	154.19
45+		0.00	74.07	231.21	421.94	313.39	256.41
unknown		---	---	---	---	---	---

nr = not reported
* data include only 1 year
year 2008: cases <5 are considered 2.5

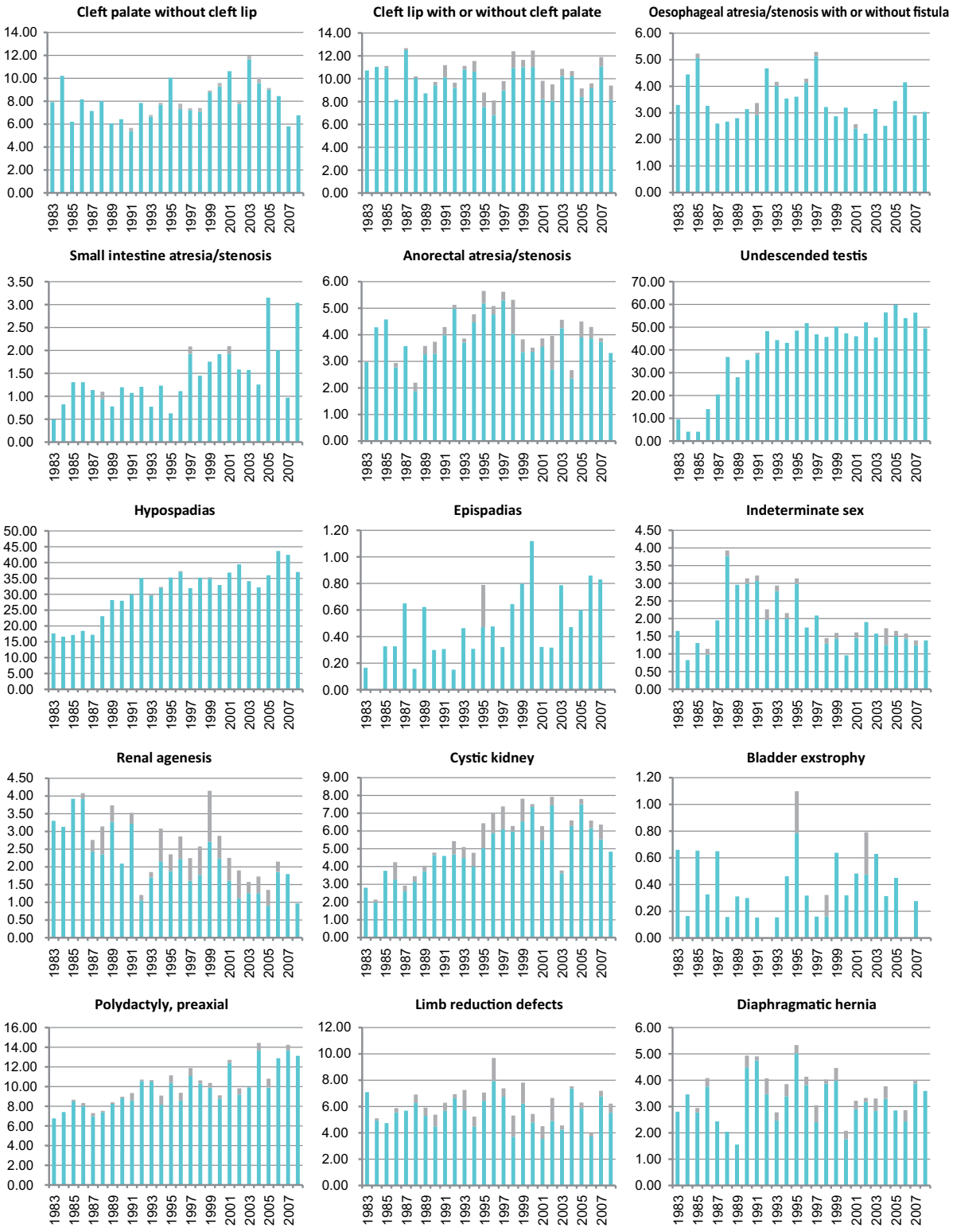
Australia: VBDR

Time trends 1983-2008 (Birth prevalence rates per 10,000)



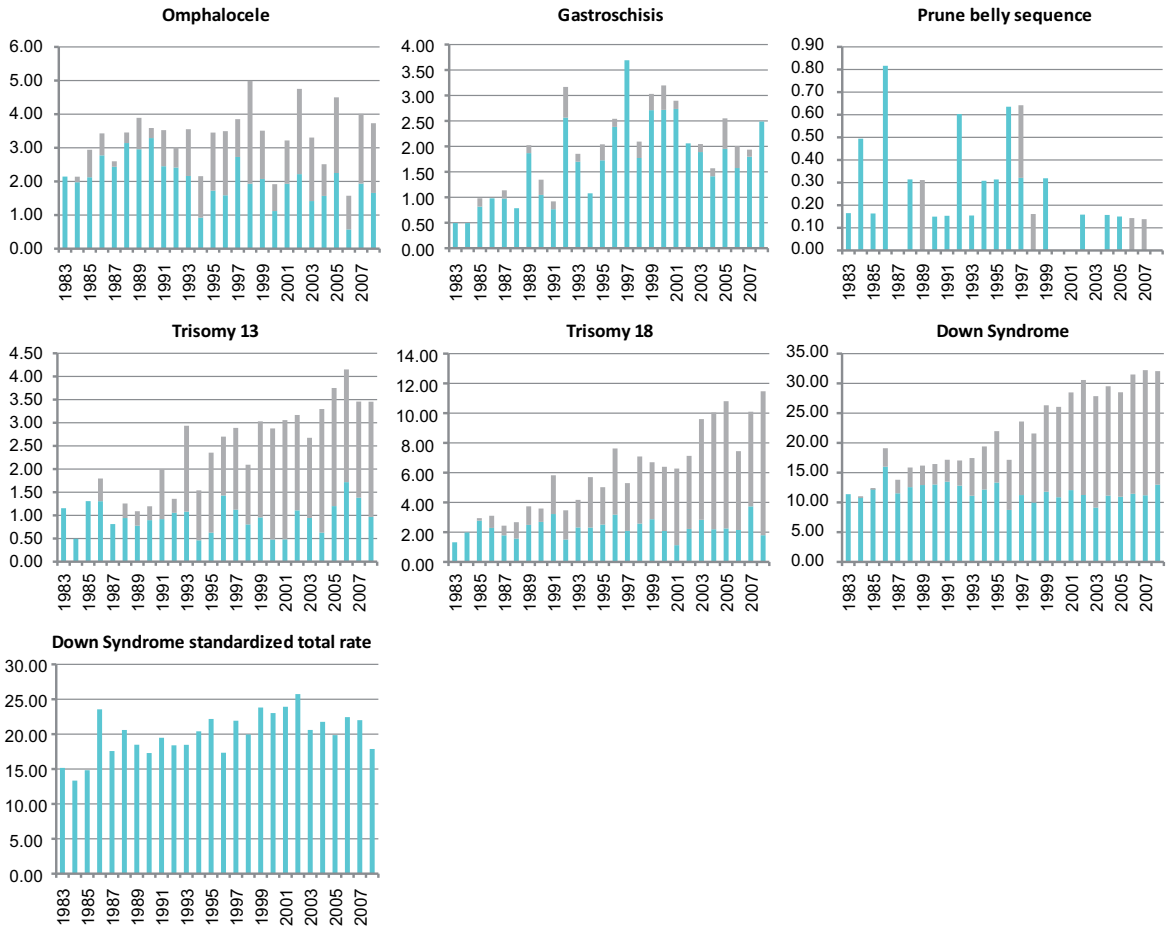
Note: L+S rates, ToP rates

Australia: VBDR



Note: L+S rates, ToP rates

Australia: VBDR



Note: L+S rates, ToP rates

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 birth defects (numerators) and all births in Western Australia (denominators). Data from the Registry are provided to the National Perinatal Statistics Unit for monitoring birth defects in Australia as a whole. Further information is available on the WARDA website - http://kemh.health.wa.gov.au/services/register_developmental_anomalies/

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King Edward Memorial Hospital
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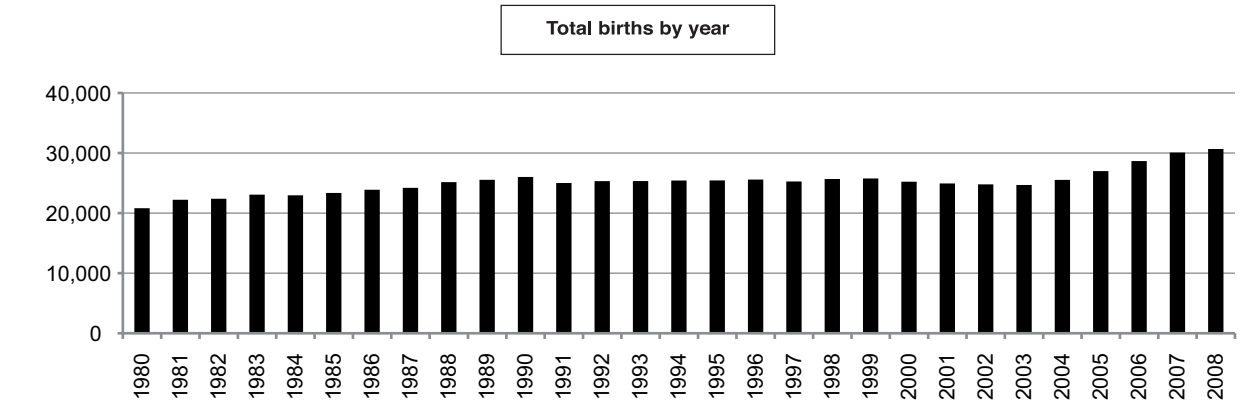
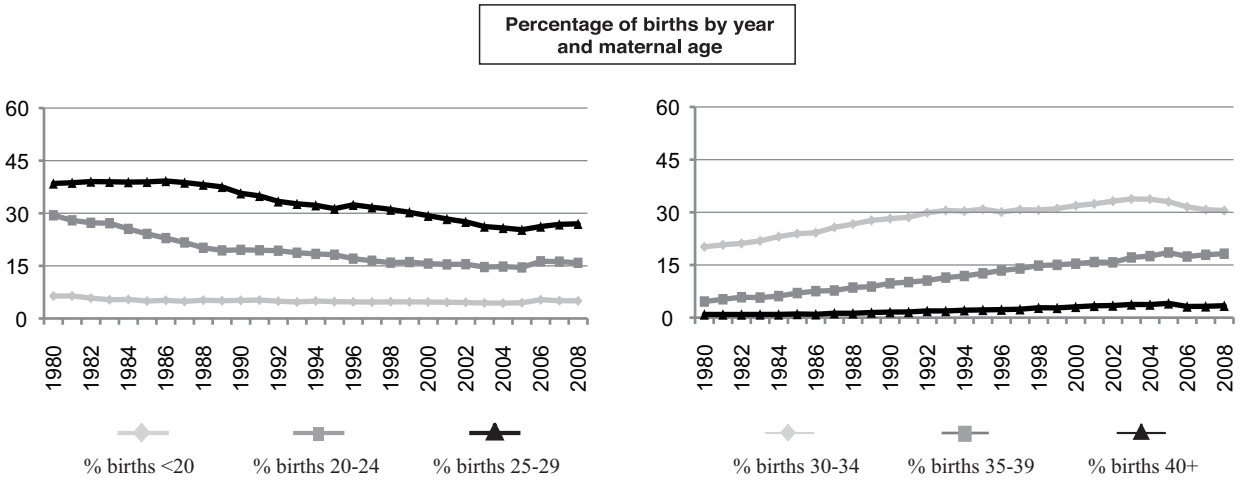
Website: http://kemh.health.wa.gov.au/services/register_developmental_anomalies/

Australia: WARDA





Terminations of pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	47	94.0	Cystic kidney	12	18.5
Spina bifida	33	67.3	Limb reduction defects	26	42.6
Encephalocele	10	71.4	Diaphragmatic hernia	5	20.8
Holoprosencephaly	12	75.0	Omphalocele	23	71.9
Hydrocephaly	45	62.5	Gastroschisis	4	9.5
Hypoplastic left heart syndrome	13	65.0	Trisomy 13	25	104.2
Cleft palate without cleft lip	12	17.4	Trisomy 18	56	83.6
Cleft lip with or without cleft palate	19	18.1	Down syndrome	148	63.8
Renal agenesis	14	34.1			

Total ToPs with births defects = 578 (Ratio ToPs/Births: 6.46 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: WARDA, 2008

Live births (LB)	30,449
Stillbirths (SB)	225
Total births	30,674
Number of terminations of pregnancy (ToP) for birth defects	185

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	19	6.52
Spina bifida	7	1	7	4.89
Encephalocele	1	0	5	1.96
Microcephaly	5	0	0	1.63
Holoprosencephaly	3	0	4	2.28
Hydrocephaly	8	1	15	7.82
Anophthalmos	0	0	1	0.33
Microphthalmos	1	0	0	0.33
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	4	0	0	1.30
Microtia	3	0	0	0.98
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	11	0	1	3.91
Tetralogy of Fallot	11	0	0	3.59
Hypoplastic left heart syndrome	3	0	6	2.93
Coarctation of aorta	17	0	0	5.54
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	23	0	5	9.13
Cleft lip with or without cleft palate	32	0	3	11.41
Oesophageal atresia/stenosis with or without fistula	10	1	2	4.24
Small intestine atresia/stenosis	9	0	0	2.93
Anorectal atresia/stenosis	7	0	4	3.59
Undescended testis (36 weeks of gestation or later)	62	0	0	20.21
Hypospadias	75	0	0	24.45
Epispadias	1	0	0	0.33
Indeterminate sex	0	0	0	0.00
Renal agenesis	1	4	7	3.91
Cystic kidney	17	0	7	7.82
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	15	0	7	7.17
Total Limb reduction defects (include unspecified)	12	0	10	7.17
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	12	0	10	7.17
Diaphragmatic hernia	6	0	0	1.96
Omphalocele	1	2	9	3.91
Gastroschisis	13	0	0	4.24
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	10	3.26
Trisomy 18	2	2	18	7.17
Down syndrome, all ages (include age unknown)	23	4	48	24.45
<20	0	0	1	6.49
20-24	2	1	1	8.22
25-29	3	0	4	8.46
30-34	4	0	8	12.83
35-39	6	2	26	60.84
40-44	7	1	8	159.36
45+	1	0	0	243.90
unknown	0	0	0	---

nr = not reported

Australia: WARDA, Previous years rates 1980 - 2008

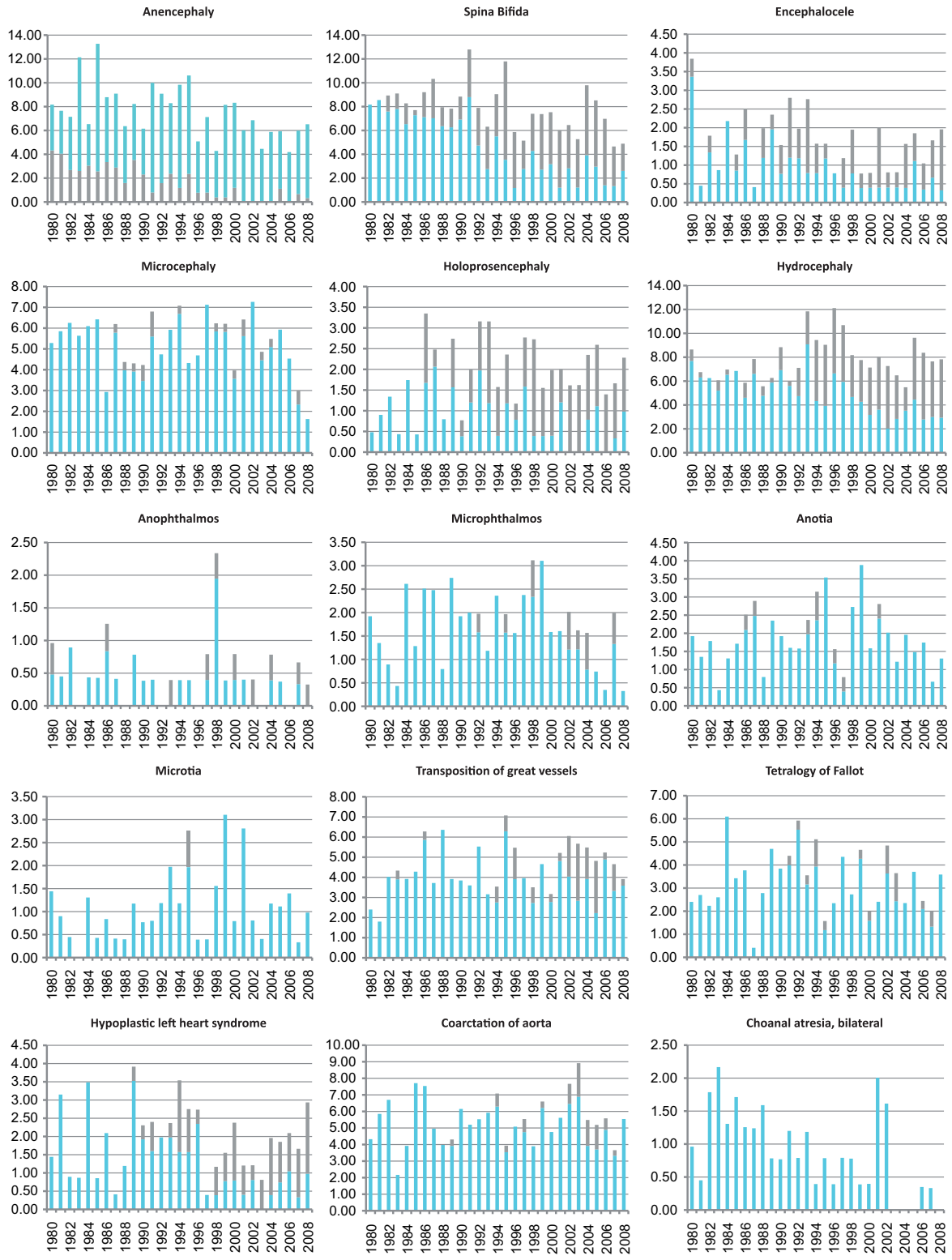
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**88,499**	**119,571**	**127,229**	**127,395**	**125,399**	**141,935**	
Anencephaly	8.81	8.78	8.33	7.38	6.78	5.71	
Spina bifida	8.70	8.70	8.72	7.77	6.54	6.83	
Encephalocele	1.69	1.67	2.28	1.41	1.04	1.62	
Microcephaly	5.76	5.19	5.19	5.89	5.82	3.95	
Holoprosencephaly	0.79	1.76	2.36	2.12	1.75	2.04	
Hydrocephaly	6.89	6.61	8.10	10.05	7.74	7.89	
Anophthalmos	0.56	0.50	0.39	0.78	0.40	0.42	
Microphthalmos	1.13	2.01	1.96	2.28	1.99	0.99	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	1.36	1.84	1.96	2.35	2.23	1.41	
Microtia	0.68	0.67	1.18	1.26	1.59	0.99	
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	3.16	4.93	4.01	4.71	4.94	4.79	
Tetralogy of Fallot	2.49	3.26	4.48	3.22	3.51	2.82	
Hypoplastic left heart syndrome	1.58	1.59	2.59	2.12	1.44	2.11	
Coarctation of aorta	4.75	5.60	5.42	5.10	6.70	5.14	
Choanal atresia, bilateral	1.36	1.42	0.94	0.63	0.88	0.14	
Cleft palate without cleft lip	7.80	8.11	11.24	10.52	12.92	8.53	
Cleft lip with or without cleft palate	11.75	13.80	10.37	12.56	12.36	12.19	
Oesophageal atresia / stenosis with or without fistula	2.94	3.60	2.52	3.38	3.67	4.58	
Small intestine atresia / stenosis	3.16	2.59	2.59	2.43	3.43	2.54	
Anorectal atresia / stenosis	5.76	4.35	7.23	5.89	6.70	5.43	
Undescended testis (36 weeks of gestation or later)	64.07	65.82	70.19	57.07	52.95	29.24	
Hypospadias	26.21	29.94	32.07	36.89	36.92	31.00	
Epispadias	0.34	0.33	0.31	0.16	0.16	0.28	
Indeterminate sex	0.00	0.33	0.39	0.31	0.24	0.07	
Renal agenesis	3.62	3.18	4.32	4.63	4.55	4.93	
Cystic kidney	2.94	3.51	6.84	7.69	9.09	7.47	
Bladder exstrophy	0.23	0.17	0.24	0.39	0.24	0.21	
Polydactyly, preaxial	9.04	11.04	10.06	12.79	11.24	9.93	
Total Limb reduction defects (include unspecified)	4.75	4.52	6.92	7.46	10.37	6.90	
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	4.75	4.52	6.92	7.46	10.37	6.90	
Diaphragmatic hernia	3.62	2.34	3.30	3.45	3.75	2.89	
Omphalocele	1.36	3.18	3.30	3.69	4.07	3.80	
Gastroschisis	1.36	1.76	2.52	3.77	3.11	3.95	
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.00	
Prune belly sequence	0.56	0.67	0.55	0.31	0.08	0.00	
Trisomy 13	0.68	1.09	1.34	1.73	2.71	3.17	
Trisomy 18	1.47	1.76	3.54	4.95	7.34	7.33	
Down syndrome, all ages (include age unknown)	11.41	15.14	16.74	18.92	24.32	27.20	
<20	3.78	8.15	6.26	6.56	13.85	8.66	
20-24	5.66	4.40	9.37	5.02	7.22	8.14	
25-29	9.03	7.98	8.57	8.90	11.80	9.65	
30-34	12.91	14.53	17.64	16.45	18.92	18.82	
35-39	44.31	51.80	37.19	43.51	46.38	59.34	
40-44	79.05	282.03	153.04	166.61	155.53	169.21	
45+	625.00	491.80	410.96	291.97	558.38	463.92	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

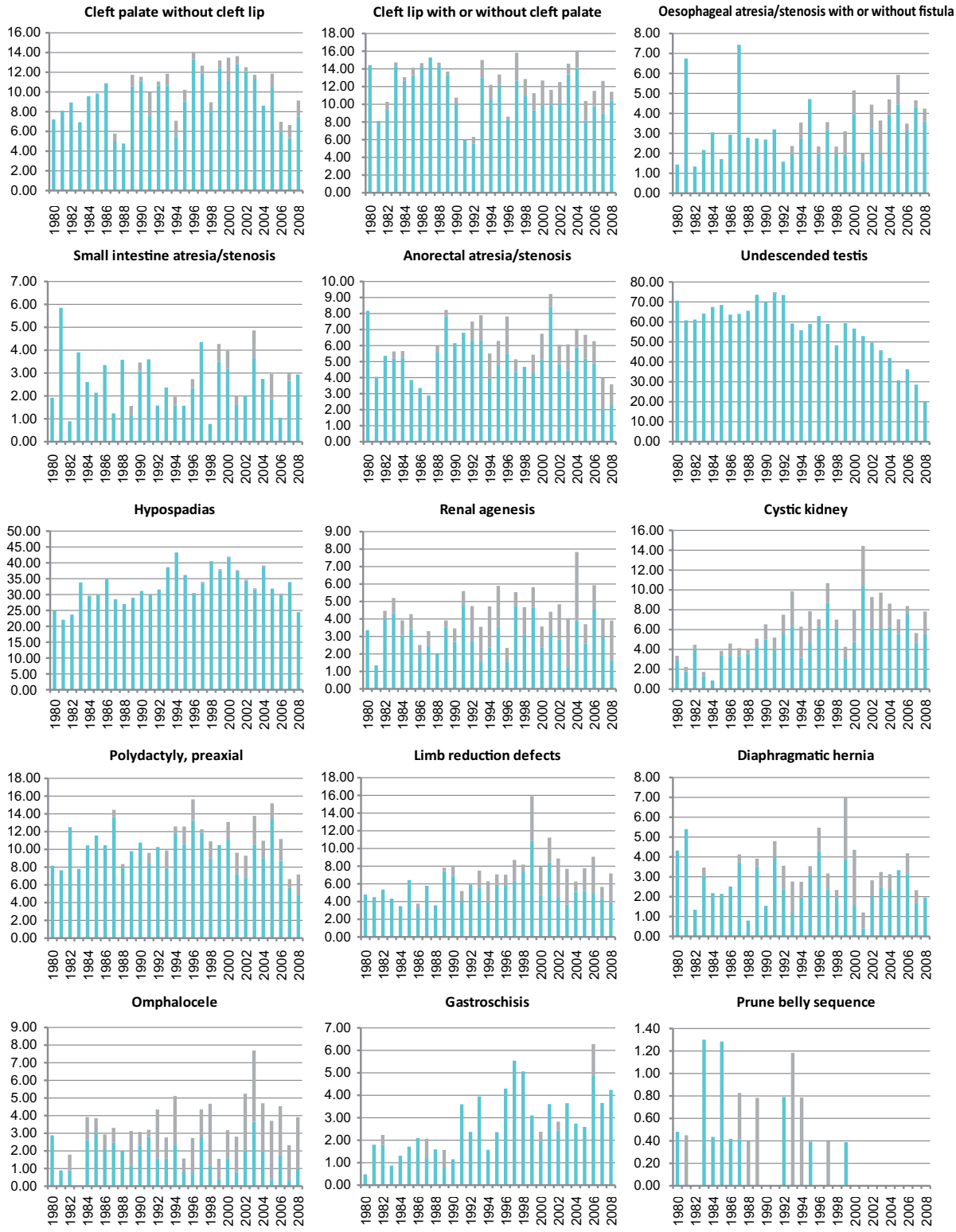
Australia: WARDA

Time trends 1980-2008 (Birth prevalence rates per 10,000)



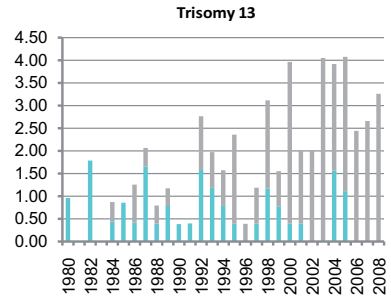
Note: L+S rates, ToP rates

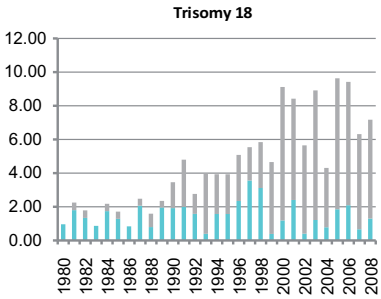
Australia: WARDA

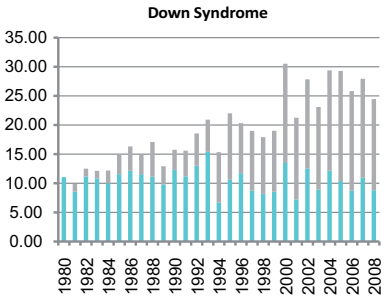


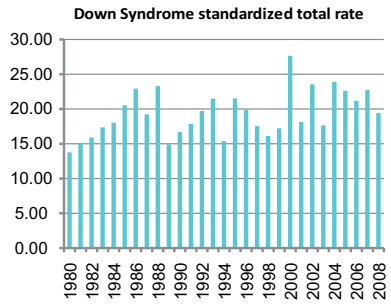
Note: L+S rates, ToP rates

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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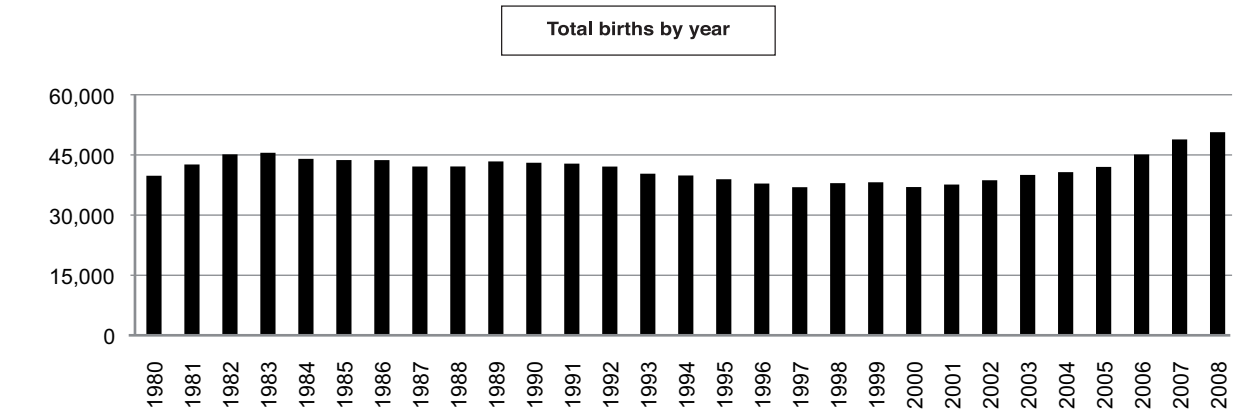
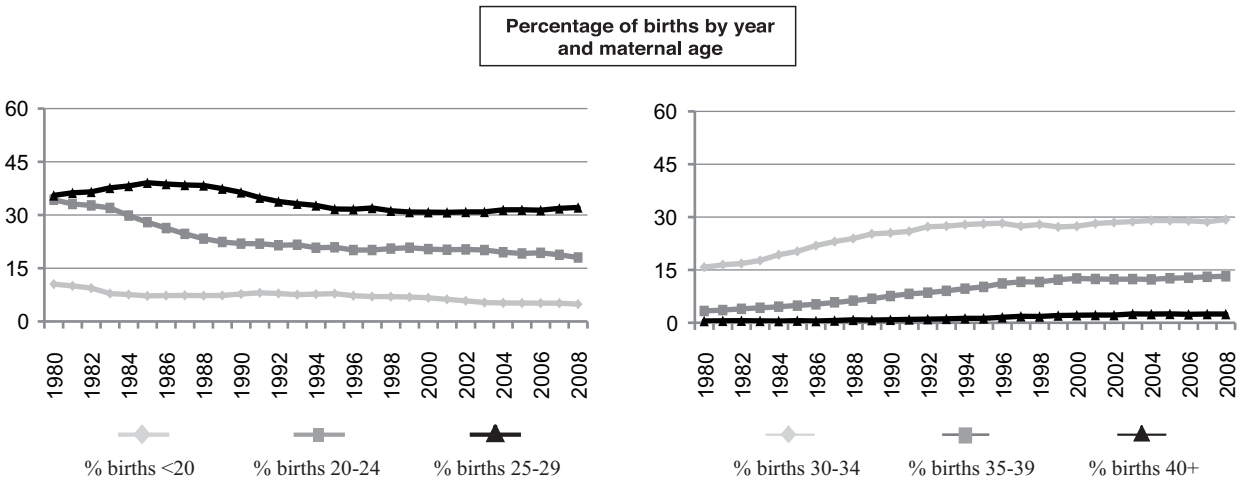
Canada-Alberta: ACASS





Terminations of pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	9	32.1	Cystic kidney	3	3.2
Spina bifida	9	13.8	Limb reduction defects	17	11.6
Encephalocele	2	14.3	Diaphragmatic hernia	3	6.1
Holoprosencephaly	8	25.0	Omphalocele	12	29.3
Hydrocephaly	5	5.2	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	19	40.4
Cleft palate without cleft lip	5	5.4	Trisomy 18	31	42.5
Cleft lip with or without cleft palate	10	5.2	Down syndrome	93	31.0
Renal agenesis	3	15.8			

Total ToPs with births defects = 255 (Ratio ToPs/Births: 1.76 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Canada-Alberta: ACASS, 2008

Live births (LB)	50,164
Stillbirths (SB)	348
Total births	50,512
Number of terminations of pregnancy (ToP) for birth defects	93

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	2	5	1.98
Spina bifida	9	6	4	3.76
Encephalocele	6	1	0	1.39
Microcephaly	16	1	1	3.56
Holoprosencephaly	7	4	3	2.77
Hydrocephaly	23	4	4	6.14
Anophthalmos	3	0	1	0.79
Microphthalmos	6	0	0	1.19
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	1	0.20
Microtia	10	0	0	1.98
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	12	1	0	2.57
Tetralogy of Fallot	11	2	0	2.57
Hypoplastic left heart syndrome	8	3	0	2.18
Coarctation of aorta	26	0	2	5.54
Choanal atresia, bilateral	6	0	0	1.19
Cleft palate without cleft lip	35	3	2	7.92
Cleft lip with or without cleft palate	55	5	5	12.87
Oesophageal atresia/stenosis with or without fistula	15	0	0	2.97
Small intestine atresia/stenosis	7	0	1	1.58
Anorectal atresia/stenosis	15	4	1	3.96
Undescended testis (36 weeks of gestation or later)	122	0	0	24.15
Hypospadias	119	1	0	23.76
Epispadias	3	0	0	0.59
Indeterminate sex	2	1	0	0.59
Renal agenesis	2	7	2	2.18
Cystic kidney	25	3	2	5.94
Bladder exstrophy	1	0	0	0.20
Polydactyly, preaxial	88	7	6	20.00
Total Limb reduction defects (include unspecified)	49	6	7	12.27
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	49	6	7	12.27
Diaphragmatic hernia	14	3	1	3.56
Omphalocele	10	3	6	3.76
Gastroschisis	23	0	0	4.55
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.20
Trisomy 13	4	4	7	2.97
Trisomy 18	8	7	13	5.54
Down syndrome, all ages (include age unknown)	58	10	28	19.01
<20	0	1	0	4.06
20-24	5	1	0	6.59
25-29	13	1	0	8.63
30-34	11	3	3	11.49
35-39	15	3	14	48.00
40-44	10	1	11	185.81
45+	4	0	0	588.24
unknown	0	0	0	---

nr = not reported

Canada-Alberta: ACASS, Previous years rates 1980 - 2008

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

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**172,506**	**214,899**	**210,881**	**191,719**	**191,018**	**226,636**	
Anencephaly	3.59	3.26	2.47	2.57	2.36	2.07	
Spina bifida	4.58	5.58	4.79	5.29	2.94	4.10	
Encephalocele	1.04	0.98	0.81	1.21	1.52	1.15	
Microcephaly	3.25	3.58	3.51	2.73	3.93	3.75	
Holoprosencephaly	0.46	0.65	1.09	1.41	2.04	2.03	
Hydrocephaly	6.38	5.12	5.12	4.87	5.66	6.22	
Anophthalmos	0.23	0.33	0.57	0.21	0.42	0.31	
Microphthalmos	0.93	1.16	1.19	0.84	1.42	1.63	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	0.06	0.19	0.24	0.37	0.63	0.35	
Microtia	0.23	0.70	0.90	1.10	1.26	2.16	
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	2.90	3.16	2.94	3.35	3.83	3.49	
Tetralogy of Fallot	1.74	2.70	3.22	2.04	2.10	2.47	
Hypoplastic left heart syndrome	1.91	2.65	1.80	2.52	2.73	3.22	
Coarctation of aorta	2.96	4.65	4.36	4.82	3.09	3.93	
Choanal atresia, bilateral	0.81	1.54	1.90	1.47	1.84	1.54	
Cleft palate without cleft lip	6.32	7.12	7.78	8.33	8.44	6.93	
Cleft lip with or without cleft palate	10.15	11.68	11.95	12.11	11.96	12.75	
Oesophageal atresia / stenosis with or without fistula	2.61	3.12	2.56	2.31	2.15	2.34	
Small intestine atresia / stenosis	0.75	0.88	1.38	1.47	1.99	1.41	
Anorectal atresia / stenosis	3.19	4.47	5.31	5.29	6.66	4.33	
Undescended testis (36 weeks of gestation or later)	26.67	26.52	29.92	23.53	24.33	25.24	
Hypospadias	17.16	22.52	24.85	18.92	19.87	21.63	
Epispadias	0.64	0.23	0.43	0.37	0.68	0.75	
Indeterminate sex	0.35	0.56	1.14	0.84	1.42	1.50	
Renal agenesis	2.26	2.61	2.28	1.31	1.84	1.28	
Cystic kidney	2.09	3.35	5.22	5.14	7.55	7.24	
Bladder exstrophy	0.46	0.14	0.33	0.26	0.47	0.31	
Polydactyly, preaxial	9.62	12.24	16.60	12.89	13.58	19.33	
Total Limb reduction defects (include unspecified)	5.86	8.00	10.81	10.01	12.74	10.72	
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	5.86	8.00	10.81	10.01	12.74	10.72	
Diaphragmatic hernia	3.25	3.44	2.66	2.52	4.61	3.27	
Omphalocele	1.68	2.09	2.09	2.20	2.36	2.78	
Gastroschisis	1.51	1.44	1.42	2.46	3.09	4.90	
Unspecified Omphalocele / Gastroschisis	0.70	0.37	0.43	0.16	0.00	0.00	
Prune belly sequence	0.58	0.23	0.24	0.31	0.31	0.44	
Trisomy 13	0.81	0.74	1.19	1.26	1.68	2.91	
Trisomy 18	1.28	1.86	2.04	3.35	4.35	5.25	
Down syndrome, all ages (include age unknown)	9.33	9.17	11.10	13.26	18.93	21.76	
<20	nr	5.40	4.92*	4.98	10.19	6.92	
20-24	nr	4.14	7.80*	5.37	4.63	7.71	
25-29	nr	6.56	6.74*	7.90	10.37	10.32	
30-34	nr	11.35	13.73*	12.95	16.66	15.85	
35-39	nr	36.95	24.81*	36.31	42.71	58.59	
40-44	nr	111.52	93.99*	108.92	188.45	170.44	
45+	nr	0.00	375*	246.91	196.08	513.83	
unknown	---	---	---	---	---	---	

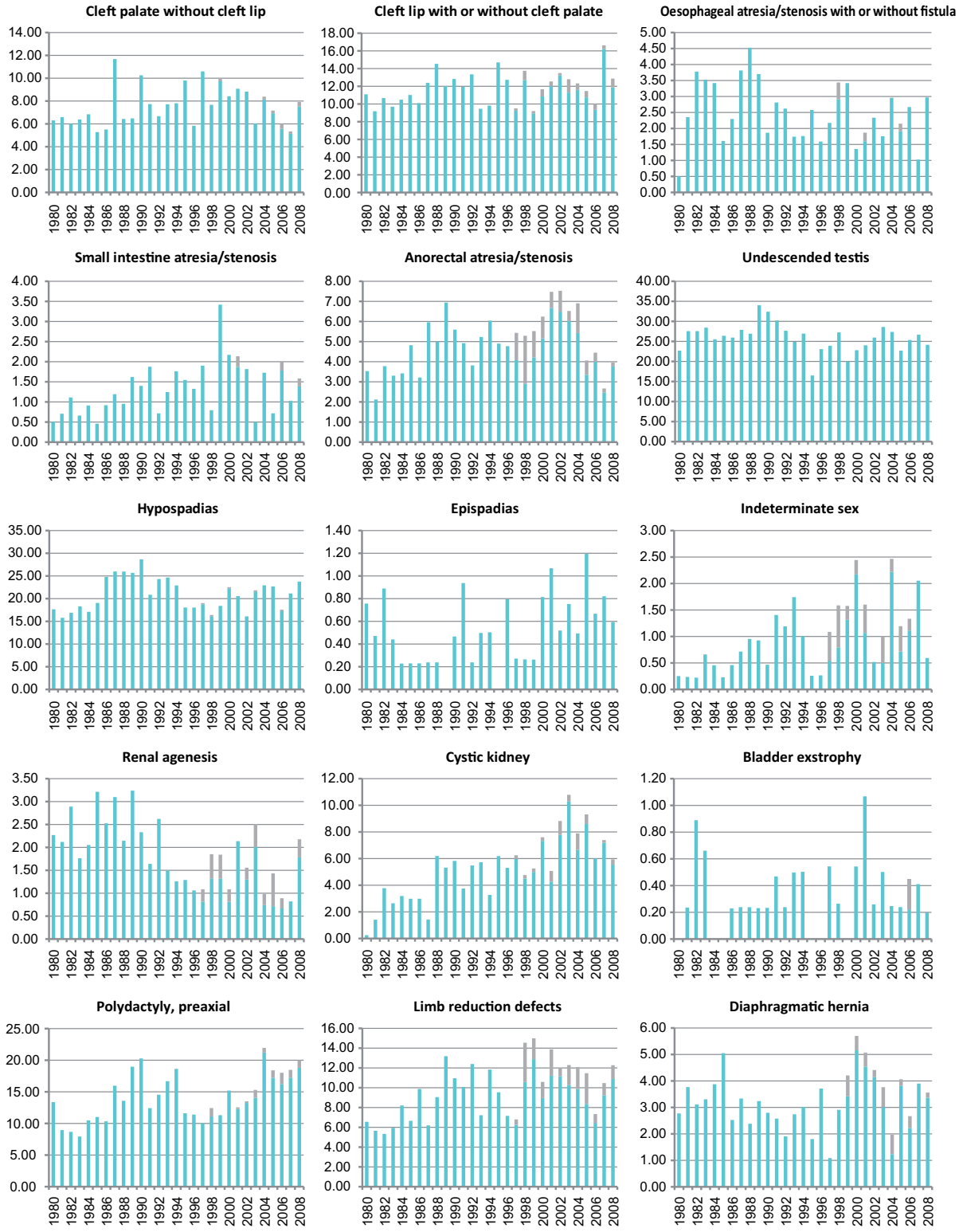
nr = not reported
* data include less than 5 years

Canada-Alberta: ACASS

Time trends 1980-2008 (Birth prevalence rates per 10,000)

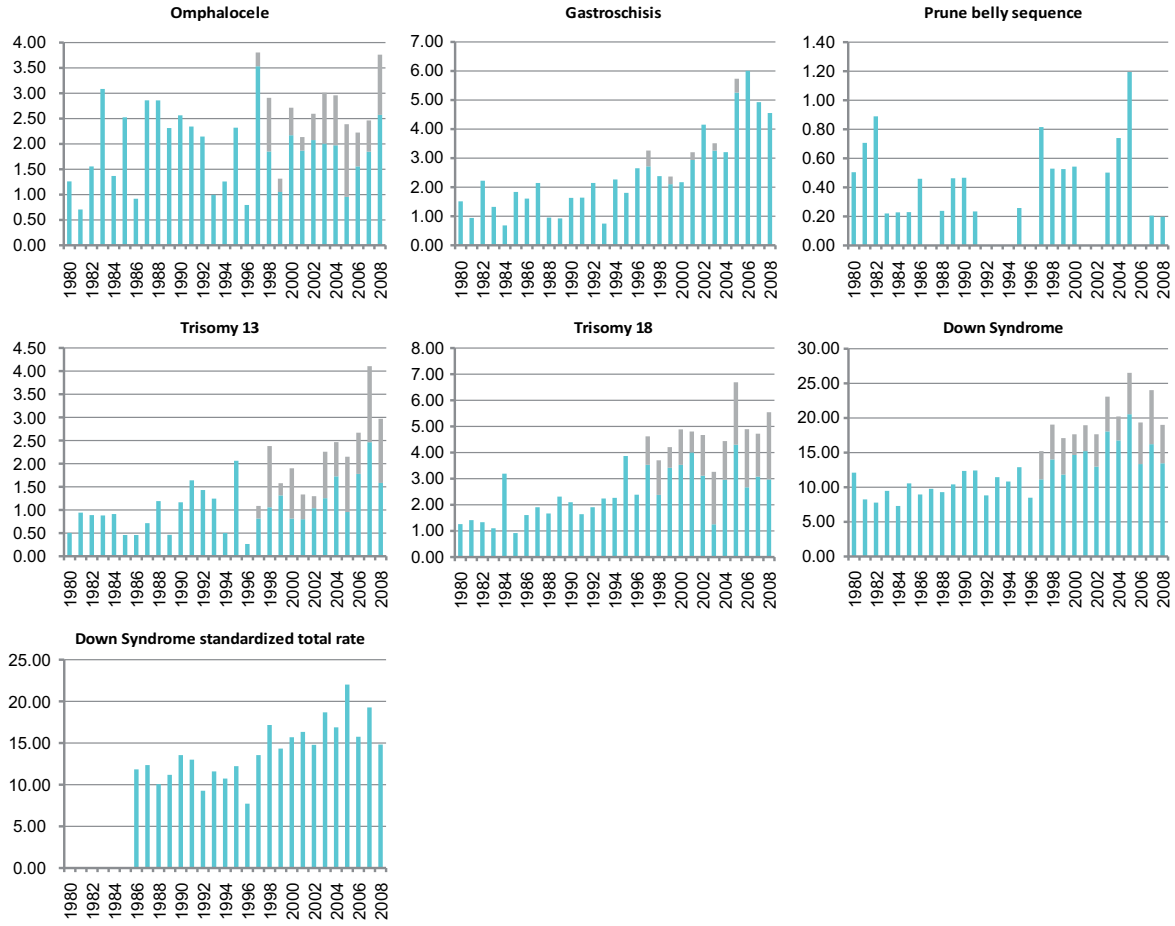
Note: L+S rates, ToP rates

Canada-Alberta: ACASS



Note: L+S rates, ToP rates

Canada-Alberta: ACASS



Note: L+S rates, ToP rates

Canada: 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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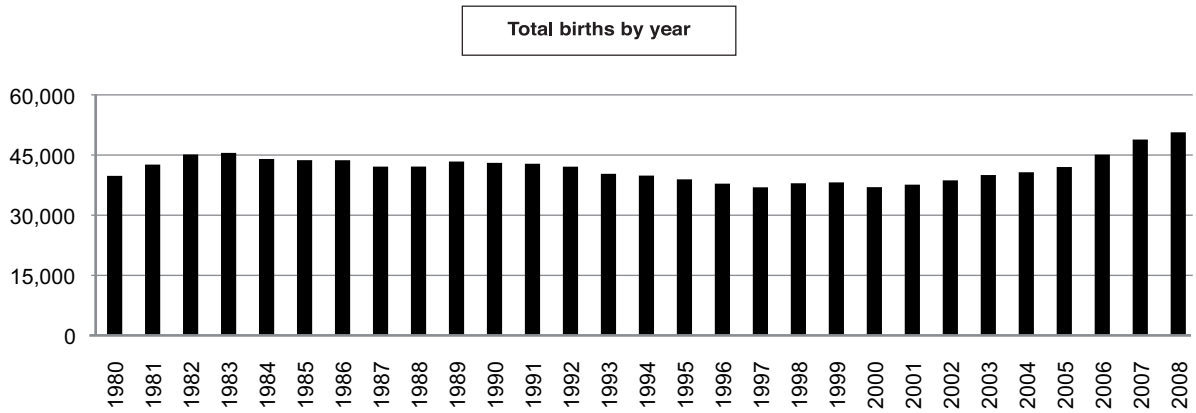
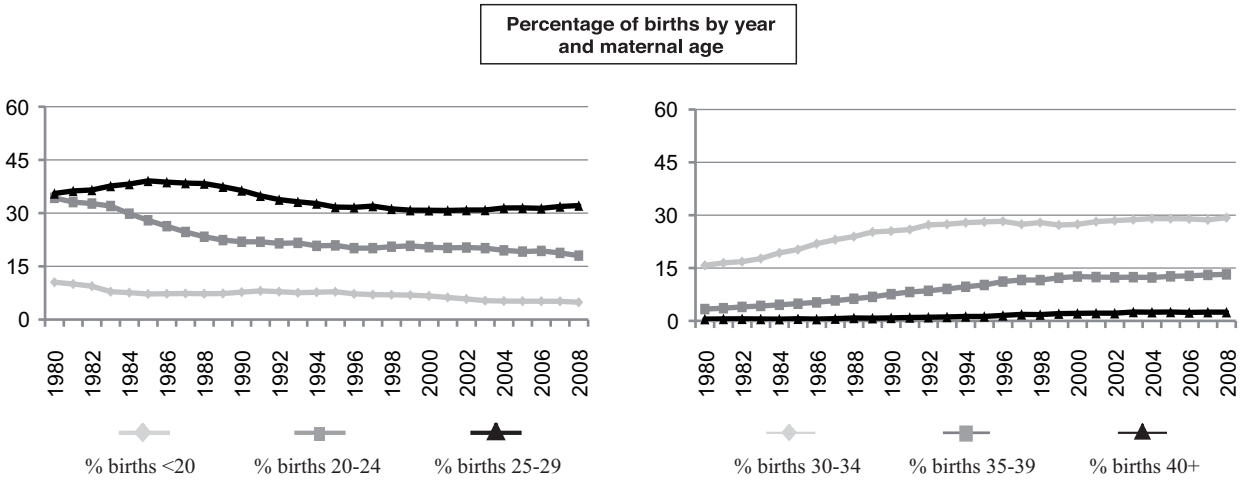
Canada: British Columbia





Canada: British Columbia, 2008

Live births (LB)	44,156
Stillbirths (SB)	424
Total births	44,580
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	3	nr	0.90
Spina bifida	5	3	nr	1.79
Encephalocele	1	1	nr	0.45
Microcephaly	28	3	nr	6.95
Holoprosencephaly	37	17	nr	12.11
Hydrocephaly	24	3	nr	6.06
Anophthalmos	3	0	nr	0.67
Microphthalmos	5	1	nr	1.35
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	12	0	nr	2.69
Unspecified Anotia/Microtia	4	0	nr	0.90
Transposition of great vessels	24	2	nr	5.83
Tetralogy of Fallot	23	4	nr	6.06
Hypoplastic left heart syndrome	10	3	nr	2.92
Coarctation of aorta	29	1	nr	6.73
Choanal atresia, bilateral	6	0	nr	1.35
Cleft palate without cleft lip	40	0	nr	8.97
Cleft lip with or without cleft palate	31	5	nr	8.08
Oesophageal atresia/stenosis with or without fistula	16	2	nr	4.04
Small intestine atresia/stenosis	15	1	nr	3.59
Anorectal atresia/stenosis	28	1	nr	6.51
Undescended testis (36 weeks of gestation or later)	198	0	nr	44.41
Hypospadias	115	0	nr	25.80
Epispadias	0	0	nr	0.00
Indeterminate sex	0	0	nr	0.00
Renal agenesis	1	3	nr	0.90
Cystic kidney	2	1	nr	0.67
Bladder exstrophy	1	0	nr	0.22
Polydactyly, preaxial	46	2	nr	10.77
Total Limb reduction defects (include unspecified)	15	1	nr	3.59
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	15	1	nr	3.59
Diaphragmatic hernia	21	3	nr	5.38
Omphalocele	4	4	nr	1.79
Gastroschisis	14	2	nr	3.59
Unspecified Omphalocele/Gastroschisis	8	1	nr	2.02
Prune belly sequence	1	0	nr	0.22
Trisomy 13	7	9	nr	3.59
Trisomy 18	5	11	nr	3.59
Down syndrome, all ages (include age unknown)	70	36	nr	23.78
<20	0	1	nr	6.67
20-24	3	1	nr	6.14
25-29	9	1	nr	8.09
30-34	24	9	nr	23.39
35-39	20	17	nr	44.54
40-44	9	7	nr	95.24
45+	3	0	nr	267.86
unknown	2	0	nr	---

nr = not reported

Canada: British Columbia, Previous years rates 1974 - 2008

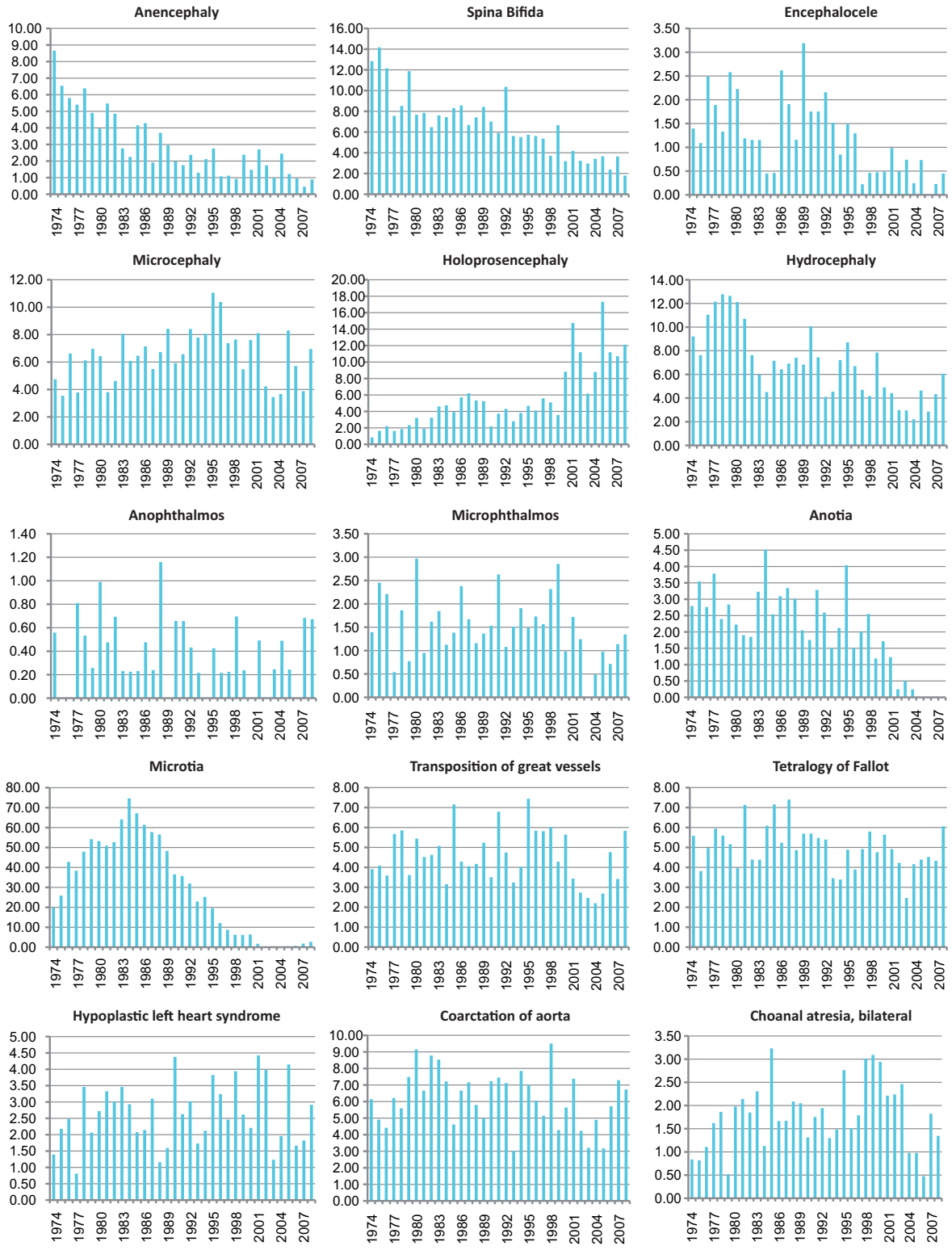
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**183,301**	**207,831**	**214,734**	**227,782**	**228,312**	**204,256**	**212,318**
Anencephaly	6.55	4.38	3.26	2.06	1.62	1.86	1.18
Spina bifida	11.02	8.23	7.68	7.46	5.21	4.06	2.97
Encephalocele	1.64	1.64	1.30	2.06	0.88	0.64	0.33
Microcephaly	4.96	5.97	6.38	7.42	8.94	5.78	5.70
Holoprosencephaly	1.64	3.08	5.17	3.64	4.64	8.86	12.01
Hydrocephaly	10.58	9.72	6.47	6.59	6.35	4.65	4.05
Anophthalmos	0.38	0.53	0.47	0.40	0.31	0.20	0.42
Microphthalmos	1.69	1.64	1.54	1.62	1.80	1.37	0.94
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	3.06	2.41	3.31	2.24	2.45	0.98	0.05
Microtia	35.08	55.09	63.61	34.95	14.59	2.94	1.22
Unspecified Anotia / Microtia	2.62	2.36	1.86	2.11	1.27	1.42	1.22
Transposition of great vessels	4.64	4.67	4.56	4.70	5.83	3.72	3.82
Tetralogy of Fallot	5.18	5.00	6.15	5.14	4.56	4.41	4.71
Hypoplastic left heart syndrome	2.07	2.94	2.28	2.68	3.11	2.89	2.50
Coarctation of aorta	5.46	8.13	6.29	5.97	7.10	4.94	5.60
Choanal atresia, bilateral	1.25	1.78	1.96	1.67	2.10	2.59	1.13
Cleft palate without cleft lip	11.02	10.92	11.83	14.00	11.91	8.62	8.62
Cleft lip with or without cleft palate	14.08	15.06	14.67	14.79	13.40	10.48	7.49
Oesophageal atresia / stenosis with or without fistula	2.95	4.14	3.35	3.07	3.77	2.99	2.59
Small intestine atresia / stenosis	2.07	3.32	3.73	3.07	4.16	4.01	4.71
Anorectal atresia / stenosis	4.86	4.67	4.42	5.40	5.08	5.24	5.84
Undescended testis (36 weeks of gestation or later)	73.70	73.33	71.53	70.99	57.33	39.90	32.69
Hypospadias	27.33	31.85	31.76	38.24	35.65	25.02	22.56
Epispadias	0.00	0.00	0.05	0.00	0.00	0.29	0.57
Indeterminate sex	1.09	1.30	1.12	0.83	1.45	0.49	0.00
Renal agenesis	5.02	5.77	7.13	6.80	5.69	3.23	0.66
Cystic kidney	3.33	4.14	5.82	6.10	6.88	2.89	0.57
Bladder exstrophy	0.38	0.43	0.65	0.44	0.35	0.39	0.52
Polydactyly, preaxial	23.19	22.09	20.58	23.40	20.67	15.57	10.22
Total Limb reduction defects (include unspecified)	10.64	8.71	8.29	6.45	6.66	3.67	3.63
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	10.64	8.71	8.29	6.45	6.66	3.67	3.63
Diaphragmatic hernia	4.96	3.99	3.26	3.95	4.82	3.08	4.05
Omphalocele	0.00	0.00	0.05	0.00	0.18	1.66	2.35
Gastroschisis	0.00	0.00	0.05	0.00	0.18	3.43	4.66
Unspecified Omphalocele / Gastroschisis	28.53	20.26	8.66	7.11	9.46	3.62	1.08
Prune belly sequence	0.00	0.00	0.05	0.00	0.04	0.10	0.28
Trisomy 13	0.65	0.63	1.07	1.01	1.40	1.42	1.93
Trisomy 18	1.20	2.12	2.19	1.76	3.28	4.01	3.72
Down syndrome, all ages (include age unknown)	12.27	14.05	13.83	15.85	17.48	17.14	18.13
<20	3.92*	8.32	7.54	10.95	10.31	8.09	8.30
20-24	6.47*	5.39	7.05	8.81	8.03	7.83	8.27
25-29	7.14*	8.41	6.45	6.19	11.10	10.23	7.52
30-34	17.72*	14.34	14.61	15.36	14.71	12.77	15.31
35-39	25.95*	36.84	18.99	22.08	28.68	30.57	34.10
40-44	171.99*	87.57	85.62	57.29	82.17	62.77	71.26
45+	322.58*	178.57	156.25	310.08	560.34	69.69	186.72
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

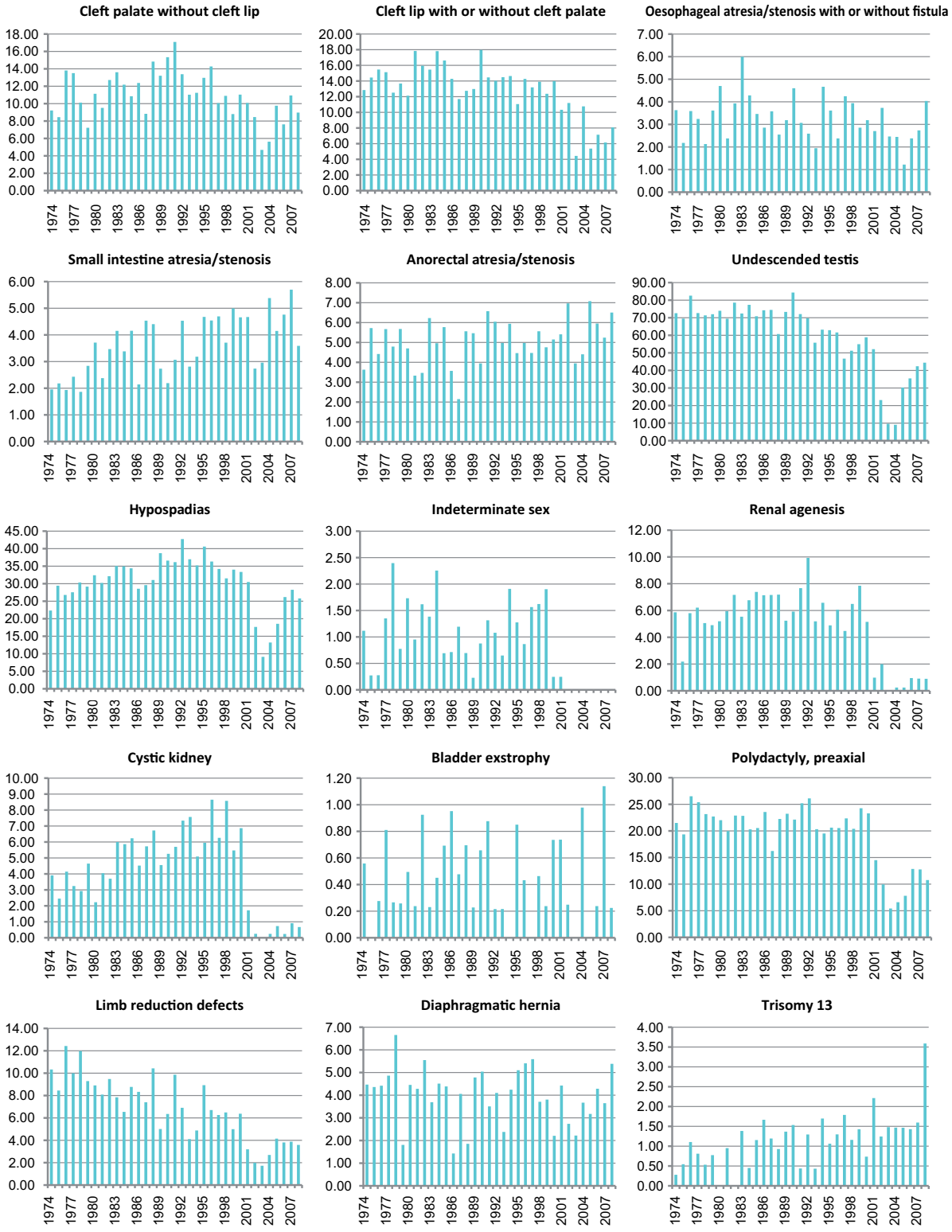
Canada: British Columbia

Time trends 1974-2008 (Birth prevalence rates per 10,000)



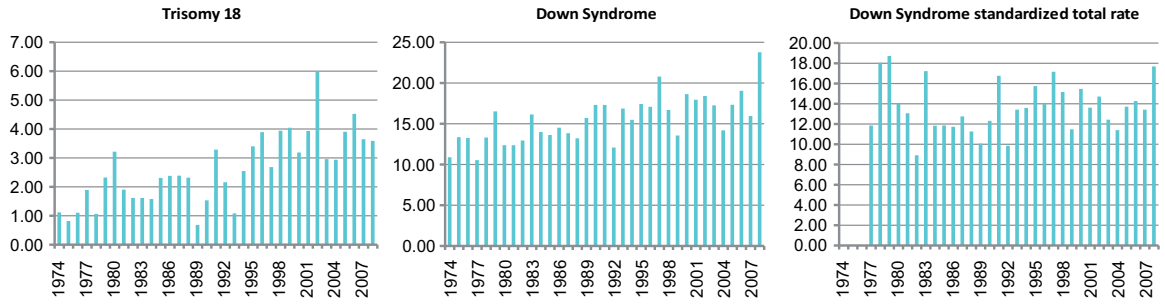
Note: L+S rates, ToP rates

Canada: British Columbia



Note: L+S rates, ToP rates

Canada: British Columbia



Note: L+S rates, ToP rates

Canada National: CCASN
Canadian Congenital Anomalies Surveillance Network

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 ICBDMS in the early 1990s, and reinstated its associate member status in 1996.

Size and coverage:
This system presently monitors about 330,000 births annually, which captures virtually all births in the 10 provinces and 3 territories of Canada. Live births to 1 year of age and registered stillbirths (a birth weight of greater or equal to 500 grams, or greater than or equal to 20 weeks in pregnancy) were captured until 2000. Since 2001, all data provided by Canadian Institute for Health Information (CIHI) only include a 30 days followup period.

Legislation and funding:
Reporting is based on an agreement between the Canadian Institute for Health Information (CIHI), a non-profit organization, which collects and disseminates data on hospital admission/ separation in Canada, and the central registry, which is run and funded by the Public Health Agency of Canada. The Alberta Congenital Anomalies Surveillance System and Med-Echo (Système de maintenance et d'exploitation des données pour l'étude de la clientèle hospitalière) for the province of Québec provide their data separately.

Sources of ascertainment:
Cases from most provinces and territories are ascertained from hospital admission/separation summary records collected by the Canadian Institute for Health Information (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 Canadian Institute for Health Information (CIHI) only include a 30 days followup period.

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

Background information:
Background information is based on hospital admission/separation summary records from the Canadian Institute for Health Information (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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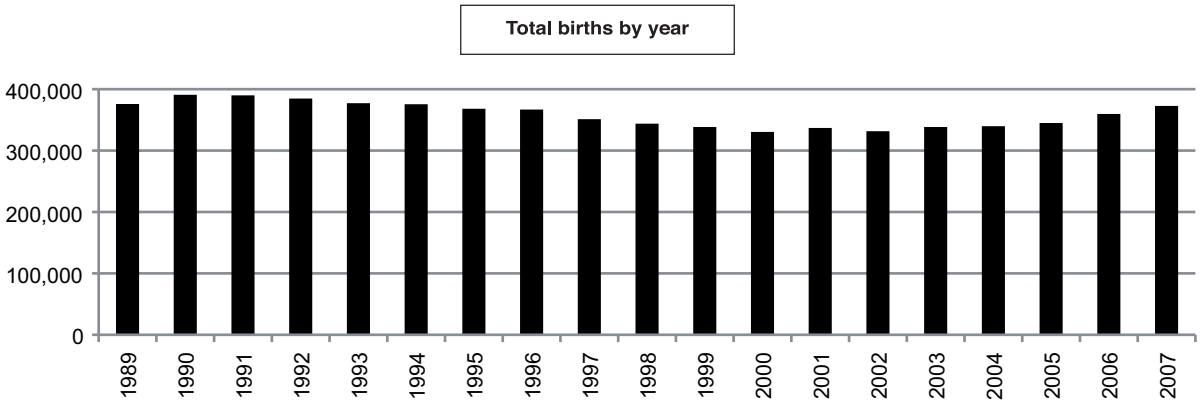
Canada National: CCASN



Canada National: CCASN, 2007*

Live births (LB)	370,124
Stillbirths (SB)	2,600
Total births	372,724
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	13	17	nr	0.80
Spina bifida	92	20	nr	3.00
Encephalocele	17	8	nr	0.67
Microcephaly	115	1	nr	3.11
Holoprosencephaly	16	7	nr	0.62
Hydrocephaly	99	22	nr	3.25
Anophthalmos	2	0	nr	0.05
Microphthalmos	8	6	nr	0.38
Unspecified Anophthalmos/Microphthalmos	10	6	nr	0.43
Anotia	4	0	nr	0.11
Microtia	34	0	nr	0.91
Unspecified Anotia/Microtia	36	0	nr	0.97
Transposition of great vessels	173	2	nr	4.70
Tetralogy of Fallot	138	5	nr	3.84
Hypoplastic left heart syndrome	76	15	nr	2.44
Coarctation of aorta	180	0	nr	4.83
Choanal atresia, bilateral	78	0	nr	2.09
Cleft palate without cleft lip	258	0	nr	6.92
Cleft lip with or without cleft palate	334	5	nr	9.10
Oesophageal atresia/stenosis with or without fistula	100	0	nr	2.68
Small intestine atresia/stenosis	140	0	nr	3.76
Anorectal atresia/stenosis	137	1	nr	3.70
Undescended testis (36 weeks of gestation or later)	1238	0	nr	33.21
Hypospadias	998	0	nr	26.78
Epispadias	26	0	nr	0.70
Indeterminate sex	52	2	nr	1.45
Renal agenesis	188	18	nr	5.53
Cystic kidney	241	10	nr	6.73
Bladder exstrophy	18	1	nr	0.51
Polydactyly, preaxial	470	3	nr	12.69
Total Limb reduction defects (include unspecified)	126	2	nr	3.43
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	126	2	nr	3.43
Diaphragmatic hernia	106	8	nr	3.06
Omphalocele	88	9	nr	2.60
Gastroschisis	150	9	nr	4.27
Unspecified Omphalocele/Gastroschisis	237	18	nr	6.84
Prune belly sequence	0	0	nr	0.00
Trisomy 13	24	19	nr	1.15
Trisomy 18	34	38	nr	1.93
Down syndrome, all ages (include age unknown)	433	75	nr	13.63
<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	---

* Data for 2007
nr = not reported

Canada National: CCASN, Previous years rates 1989 - 2007

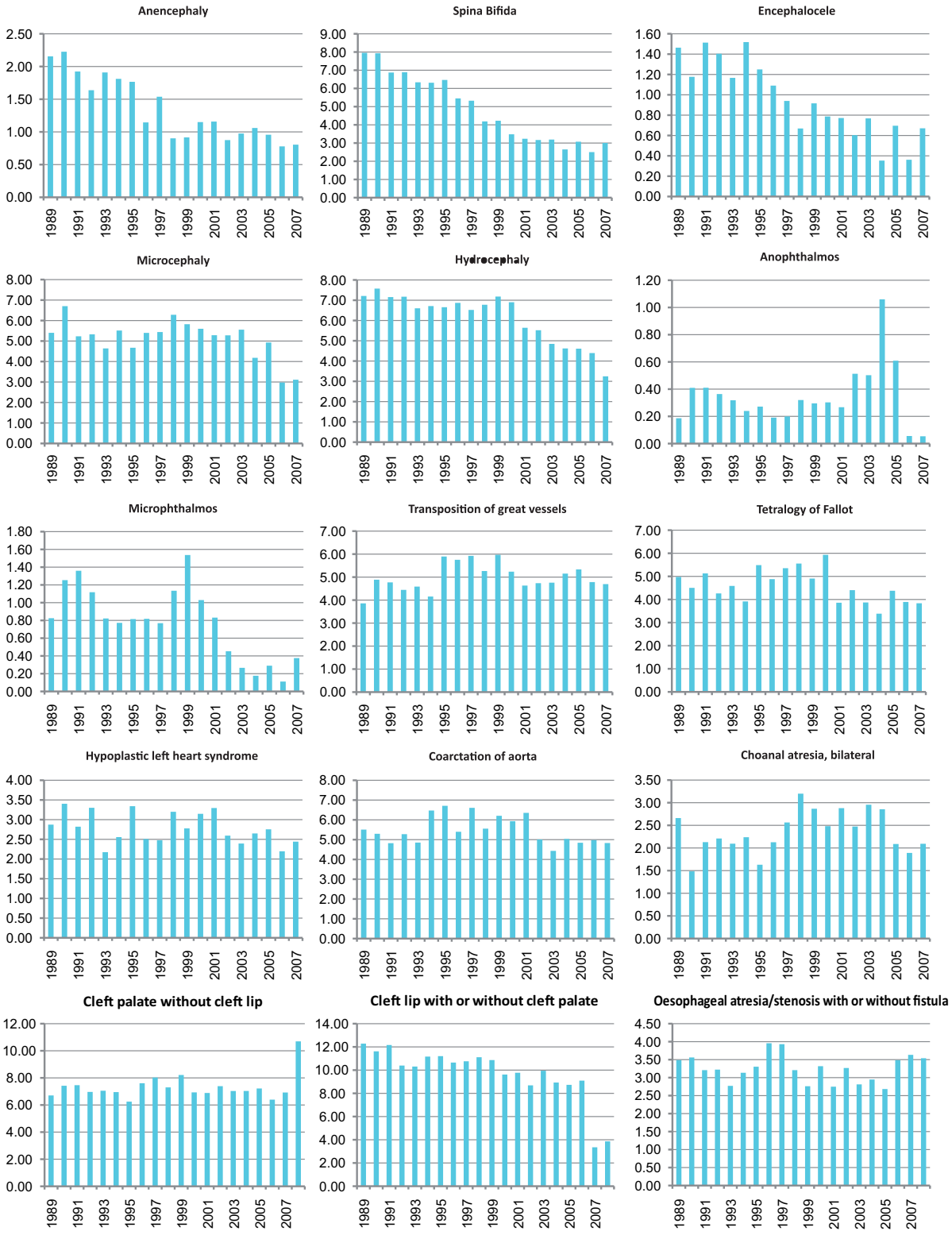
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1977	1978-1982	1983-1987	1988-1992*	1993-1997	1998-2002	2003-2007
Total births				**1,541,345**	**1,838,668**	**1,680,990**	**1,755,345**
Anencephaly				1.99	1.64	1.00	0.91
Spina bifida				7.41	5.99	3.66	2.88
Encephalocele				1.39	1.20	0.75	0.57
Microcephaly				5.67	5.13	5.66	4.12
Holoprosencephaly				nr	nr	nr	0.48*
Hydrocephaly				7.28	6.67	6.41	4.32
Anophthalmos				0.34	0.24	0.34	0.44
Microphthalmos				1.14	0.80	1.00	0.24
Unspecified Anophthalmos / Microphthalmos				0.00	0.00*	nr	0.30*
Anotia				nr	nr	nr	0.12*
Microtia				nr	nr	nr	0.78*
Unspecified Anotia / Microtia				nr	nr	nr	0.86*
Transposition of great vessels				4.50	5.25	5.17	4.94
Tetralogy of Fallot				4.72	4.84	4.93	3.87
Hypoplastic left heart syndrome				3.10	2.61	3.00	2.48
Coarctation of aorta				5.22	6.00	5.81	4.83
Choanal atresia, bilateral				2.12	2.13	2.78	2.36
Cleft palate without cleft lip				7.14	7.17	7.35	6.92
Cleft lip with or without cleft palate				11.70	10.74	10.43	9.08
Oesophageal atresia / stenosis with or without fistula				3.57	3.13	3.44	2.89
Small intestine atresia / stenosis				3.56	3.40	3.77	3.78
Anorectal atresia / stenosis				5.44	4.72	4.96	4.11
Undescended testis (36 weeks of gestation or later)				35.41	32.84	33.76	35.33
Hypospadias				27.29	26.86	27.66	27.57
Epispadias				nr	nr	nr	0.61
Indeterminate sex				0.73	0.64	0.86	1.15
Renal agenesis				5.14	4.80	5.13	5.11
Cystic kidney				4.72	5.45	6.64	6.98
Bladder exstrophy				0.45	0.40	0.32	0.46
Polydactyly, preaxial				12.40	11.45	12.79	14.05
Total Limb reduction defects (include unspecified)				4.82	4.27	4.06	3.50
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				4.82	4.27	4.06	3.50
Diaphragmatic hernia				3.71	3.63	3.72	3.12
Omphalocele				5.13	5.92*	nr	2.18*
Gastroschisis				nr	nr	nr	4.00*
Unspecified Omphalocele / Gastroschisis				nr	6.34*	6.67	6.13*
Prune belly sequence				nr	nr	nr	1.97*
Trisomy 13				1.19	1.12	1.18	1.08
Trisomy 18				2.15	2.27	2.40	2.18
Down syndrome, all ages (include age unknown)				13.23	12.90	14.57	14.44
<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 = not reported
* data include less than 5 years

Canada National: CCASN

Time trends 1989-2007 (Birth prevalence rates per 10,000)



Note: L+S rates

Canada National: CCASN

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

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

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

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

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

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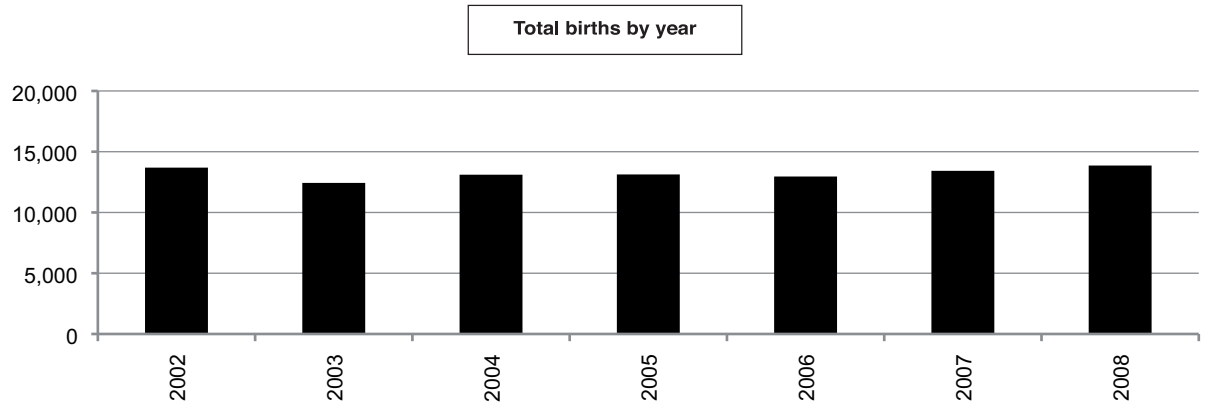
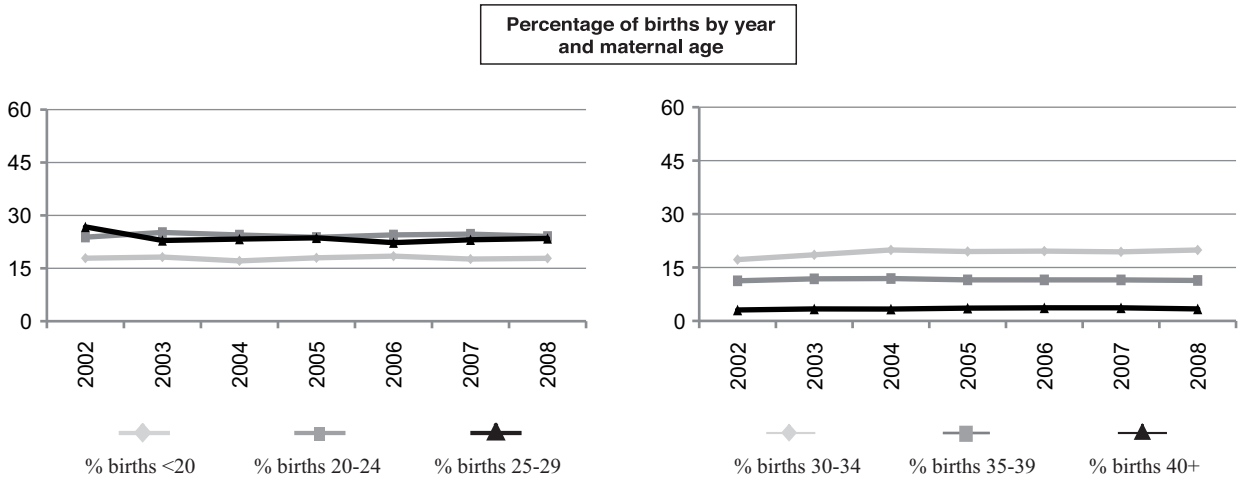
Chile-Maule: RRMC-SSM





Chile-Maule: RRMC-SSM, 2008

Live births (LB)	13,768
Stillbirths (SB)	94
Total births	13,862
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1		0.72
Spina bifida	0	0		0.00
Encephalocele	1	0		0.72
Microcephaly	1	0		0.72
Holoprosencephaly	0	0		0.00
Hydrocephaly	2	0		1.44
Anophthalmos	0	0		0.00
Microphthalmos	0	0		0.00
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	3	0		2.16
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	2	0		1.44
Tetralogy of Fallot	1	0		0.72
Hypoplastic left heart syndrome	1	0		0.72
Coarctation of aorta	2	0		1.44
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	5	1		4.33
Cleft lip with or without cleft palate	12	1		9.38
Oesophageal atresia/stenosis with or without fistula	2	0		1.44
Small intestine atresia/stenosis	1	1		1.44
Anorectal atresia/stenosis	3	1		2.89
Undescended testis (36 weeks of gestation or later)	17	0		12.26
Hypospadias	17	0		12.26
Epispadias	0	0		0.00
Indeterminate sex	1	1		1.44
Renal agenesis	3	1		2.89
Cystic kidney	2	0		1.44
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	1	0		0.72
Total Limb reduction defects (include unspecified)	1	0		0.72
Transverse	0	0		0.00
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	1	0		0.72
Mixed	0	0		0.00
Unspecified	0	0		0.00
Diaphragmatic hernia	1	0		0.72
Omphalocele	4	0		2.89
Gastroschisis	3	0		2.16
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	1	0		0.72
Trisomy 13	1	0		0.72
Trisomy 18	3	2		3.61
Down syndrome, all ages (include age unknown)	19	0		13.71
<20	0	0		0.00
20-24	3	0		9.00
25-29	1	0		3.07
30-34	3	0		10.87
35-39	6	0		38.10
40-44	6	0		136.36
45+	0	0		0.00
unknown	0	0		---

Chile-Maule: RRMC-SSM, Previous years rates 2002 - 2008

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

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003*	2004-2008
Total births						**26,122**	**66,483**
Anencephaly						3.45	1.80
Spina bifida						3.06	1.65
Encephalocele						1.15	1.20
Microcephaly						1.15	1.50
Holoprosencephaly						0.38	0.15
Hydrocephaly						2.30	1.80
Anophthalmos						0.38	0.00
Microphthalmos						1.15	0.45
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.77	0.00
Microtia						2.30	2.56
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						1.91	1.20
Tetralogy of Fallot						1.53	0.90
Hypoplastic left heart syndrome						0.38	0.45
Coarctation of aorta						0.00	0.30
Choanal atresia, bilateral						1.15	0.15
Cleft palate without cleft lip						6.51	3.76
Cleft lip with or without cleft palate						12.63	10.68
Oesophageal atresia / stenosis with or without fistula						0.77	1.35
Small intestine atresia / stenosis						1.15	1.05
Anorectal atresia / stenosis						2.30	2.71
Undescended testis (36 weeks of gestation or later)						6.13	9.78
Hypospadias						9.95	7.97
Epispadias						0.00	0.15
Indeterminate sex						1.15	0.60
Renal agenesis						0.77	1.20
Cystic kidney						0.00	1.20
Bladder exstrophy						0.00	0.15
Polydactyly, preaxial						7.66	6.02
Total Limb reduction defects (include unspecified)						3.06	3.91
Transverse						1.15	2.71
Preaxial						0.00	0.30
Postaxial						0.00	0.00
Intercalary						0.00	0.15
Mixed						0.00	0.00
Unspecified						1.91	0.75
Diaphragmatic hernia						1.15	1.05
Omphalocele						1.15	1.80
Gastroschisis						1.15	2.11
Unspecified Omphalocele / Gastroschisis						0.00	0.45
Prune belly sequence						0.38	0.30
Trisomy 13						2.30	0.75
Trisomy 18						0.77	1.80
Down syndrome, all ages (include age unknown)						17.61	23.01
<20						2.12	10.15
20-24						0.00	8.68
25-29						10.76	5.85
30-34						10.72	15.31
35-39						56.46	63.79
40-44						186.34	201.07
45+						285.71	366.97
unknown						---	---

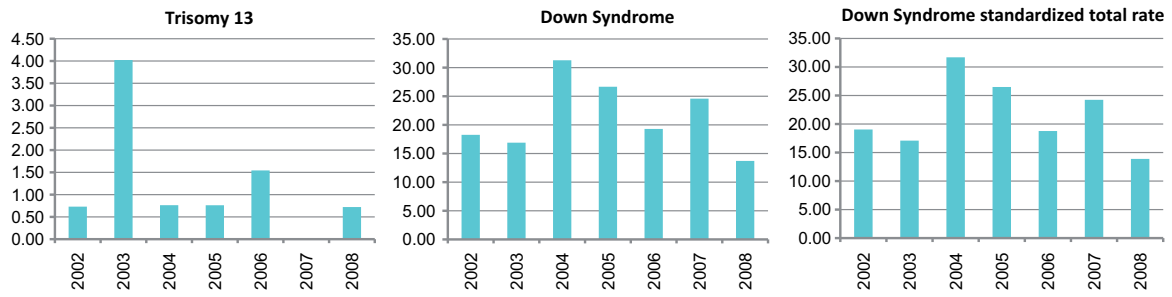
* data include only 1 year

Chile-Maule: RRMC-SSM

Time trends 2002-2008 (Birth prevalence rates per 10,000)

Note: L+S rates

Chile-Maule: RRMC-SSM



Note: L+S rates

Costa Rica: CREC
Costa Rica Register of Congenital Malformation

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:
Reporting is made by neonatologists, pediatricians and physicians before newborns discharge from maternity services, with biostatistics personal collaboration.

Exposure information:
None is routinely collected at present.

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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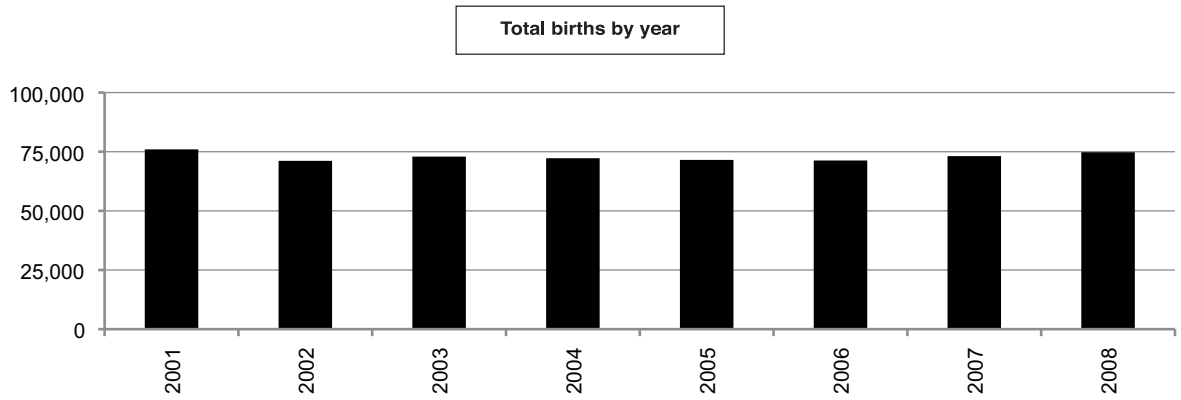
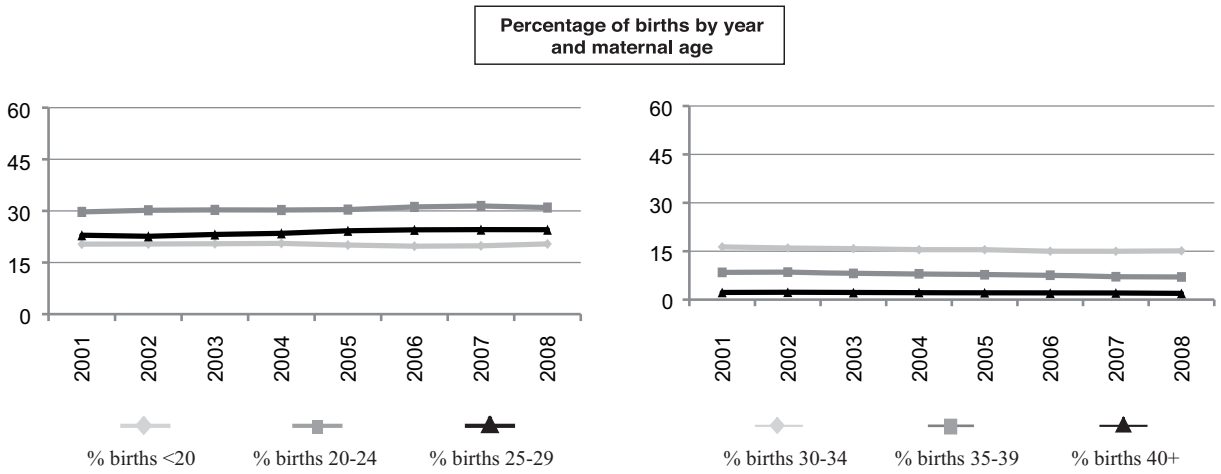
Costa Rica: CREC





Costa Rica: CREC, 2008

Live births (LB)	74,284
Stillbirths (SB)	501
Total births	74,785
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	11	1		1.60
Spina bifida	18	1		2.54
Encephalocele	6	0		0.80
Microcephaly	16	1		2.27
Holoprosencephaly	8	0		1.07
Hydrocephaly	26	3		3.88
Anophthalmos	1	0		0.13
Microphthalmos	1	0		0.13
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	1	0		0.13
Microtia	14	0		1.87
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	5	0		0.67
Tetralogy of Fallot	4	0		0.53
Hypoplastic left heart syndrome	5	0		0.67
Coarctation of aorta	3	0		0.40
Choanal atresia, bilateral	1	0		0.13
Cleft palate without cleft lip	13	0		1.74
Cleft lip with or without cleft palate	61	0		8.16
Oesophageal atresia/stenosis with or without fistula	13	0		1.74
Small intestine atresia/stenosis	3	0		0.40
Anorectal atresia/stenosis	17	0		2.27
Undescended testis (36 weeks of gestation or later)	80	0		10.70
Hypospadias	59	0		7.89
Epispadias	0	0		0.00
Indeterminate sex	10	0		1.34
Renal agenesis	7	1		1.07
Cystic kidney	15	1		2.14
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	77	0		10.30
Total Limb reduction defects (include unspecified)	30	1		4.15
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	30	1		4.15
Diaphragmatic hernia	8	3		1.47
Omphalocele	10	1		1.47
Gastroschisis	16	2		2.41
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	1	0		0.13
Trisomy 13	3	0		0.40
Trisomy 18	6	1		0.94
Down syndrome, all ages (include age unknown)	68	0		9.09
<20	12	0		7.92
20-24	11	0		4.78
25-29	8	0		4.39
30-34	7	0		6.23
35-39	14	0		26.84
40-44	13	0		95.80
45+	3	0		361.45
unknown	0	0		---

nr = not reported

Costa Rica: CREC, Previous years rates 2001 - 2008

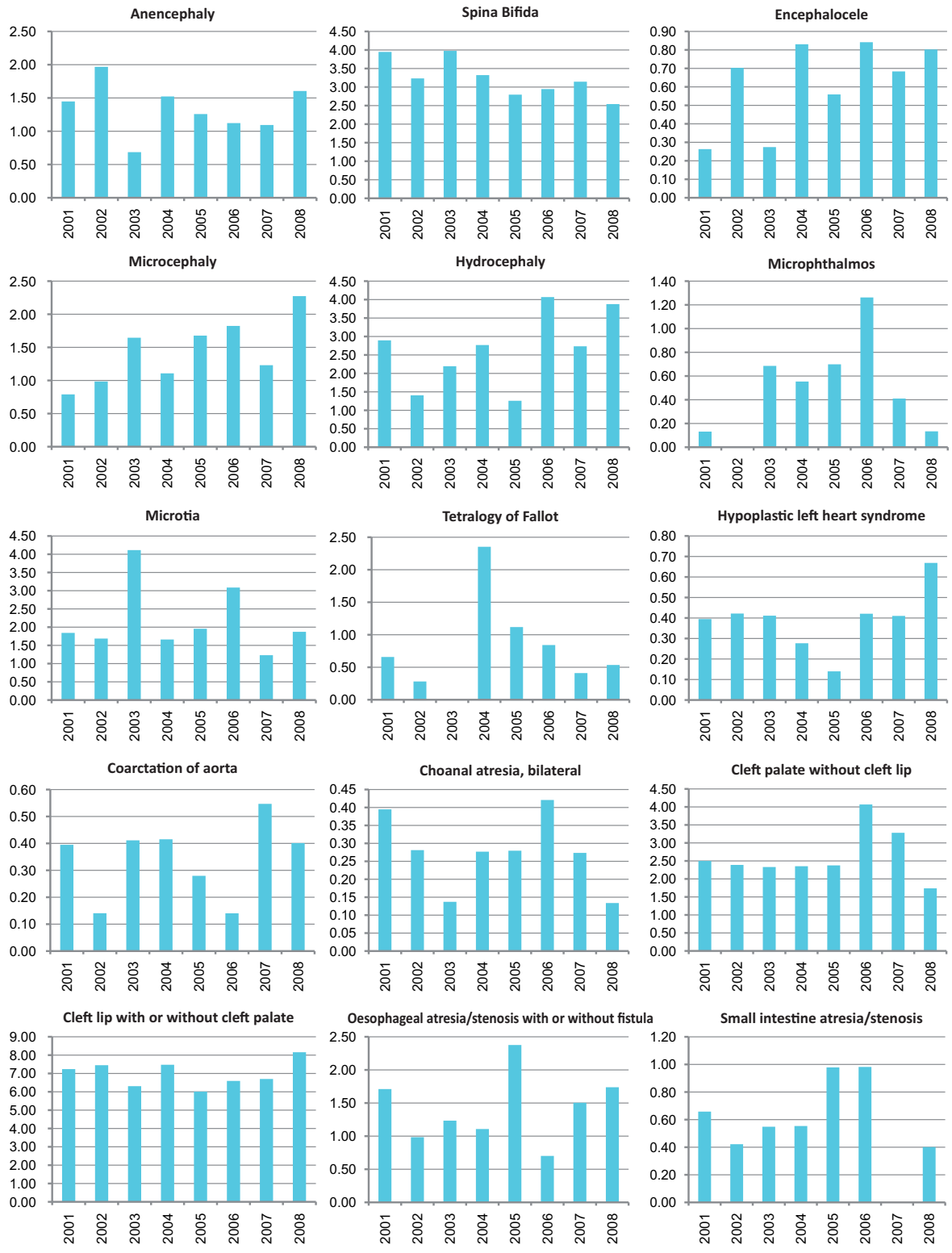
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003*	2004-2008
Total births						**220,073**	**363,015**
Anencephaly						1.36	1.32
Spina bifida						3.73	2.95
Encephalocele						0.41	0.74
Microcephaly						1.14	1.63
Holoprosencephaly						0.32	0.63
Hydrocephaly						2.18	2.95
Anophthalmos						0.23	0.25
Microphthalmos						0.27	0.61
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.14	0.72
Microtia						2.54	1.96
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						0.09	0.44
Tetralogy of Fallot						0.32	1.05
Hypoplastic left heart syndrome						0.41	0.39
Coarctation of aorta						0.32	0.36
Choanal atresia, bilateral						0.27	0.28
Cleft palate without cleft lip						2.41	2.75
Cleft lip with or without cleft palate						7.00	7.00
Oesophageal atresia / stenosis with or without fistula						1.32	1.49
Small intestine atresia / stenosis						0.55	0.58
Anorectal atresia / stenosis						2.32	3.00
Undescended testis (36 weeks of gestation or later)						9.81	9.78
Hypospadias						5.91	6.80
Epispadias						0.05	0.08
Indeterminate sex						1.77	1.63
Renal agenesis						0.41	0.96
Cystic kidney						0.27	0.88
Bladder exstrophy						0.05	0.06
Polydactyly, preaxial						5.86	10.58
Total Limb reduction defects (include unspecified)						4.95	4.57
Transverse						nr	nr
Preaxial						nr	nr
Postaxial						nr	nr
Intercalary						nr	nr
Mixed						nr	nr
Unspecified						4.95	4.57
Diaphragmatic hernia						1.73	1.43
Omphalocele						0.41	1.13
Gastroschisis						1.54	1.85
Unspecified Omphalocele / Gastroschisis						0.27	0.00
Prune belly sequence						0.14	0.44
Trisomy 13						1.50	0.61
Trisomy 18						0.77	1.07
Down syndrome, all ages (include age unknown)						8.36	8.43
<20						5.59	4.40
20-24						5.31	4.04
25-29						4.38	3.88
30-34						6.53	5.10
35-39						22.88	30.01
40-44						68.03	88.21
45+						151.98	196.51
unknown						---	---

nr = not reported
* data include less than 5 years

Costa Rica: CREC

Time trends 2001-2008 (Birth prevalence rates per 10,000)



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 Ministery 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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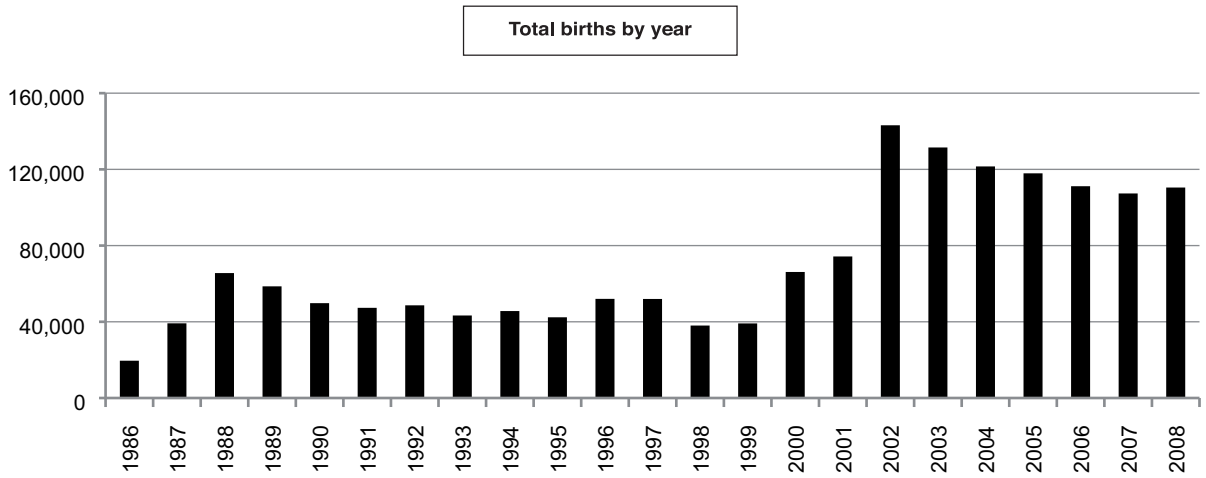
Cuba: RECUMAC



Terminations of pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	119	99.2	Cystic kidney	103	78.6
Spina bifida	162	89.0	Limb reduction defects	25	30.5
Encephalocele	59	90.8	Diaphragmatic hernia	76	82.6
Holoprosencephaly	22	84.6	Omphalocele	63	90.0
Hydrocephaly	292	89.3	Gastroschisis	206	92.4
Hypoplastic left heart syndrome	62	87.3	Trisomy 13	36	67.9
Cleft palate without cleft lip	0	0.0	Trisomy 18	51	78.5
Cleft lip with or without cleft palate	42	26.4	Down syndrome	165	38.6
Renal agenesis	32	72.7			

Total ToPs with births defects = 3,361 (Ratio ToPs/Births: 10.22 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Cuba: RECUMAC, 2008

Live births (LB)	108,657
Stillbirths (SB)	1,812
Total births	110,469
Number of terminations of pregnancy (ToP) for birth defects	1,222

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	18	1.63
Spina bifida	10	0	60	6.34
Encephalocele	2	1	14	1.54
Microcephaly	3	0	2	0.45
Holoprosencephaly	2	0	15	1.54
Hydrocephaly	14	0	81	8.60
Anophthalmos	1	0	0	0.09
Microphthalmos	2	0	1	0.27
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.18
Microtia	5	0	0	0.45
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	1	6	1.18
Tetralogy of Fallot	4	0	18	1.99
Hypoplastic left heart syndrome	1	1	20	1.99
Coarctation of aorta	1	0	0	0.09
Choanal atresia, bilateral	1	0	0	0.09
Cleft palate without cleft lip	21	0	0	1.90
Cleft lip with or without cleft palate	34	0	15	4.44
Oesophageal atresia/stenosis with or without fistula	12	1	8	1.90
Small intestine atresia/stenosis	8	0	19	2.44
Anorectal atresia/stenosis	14	0	6	1.81
Undescended testis (36 weeks of gestation or later)	20	0	0	1.81
Hypospadias	92	0	0	8.33
Epispadias	7	0	0	0.63
Indeterminate sex	2	0	0	0.18
Renal agenesis	3	0	22	2.26
Cystic kidney	4	0	49	4.80
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	11	0	0	1.00
Total Limb reduction defects (include unspecified)	19	0	6	2.26
Transverse	10	0	4	1.27
Preaxial	0	0	2	0.18
Postaxial	0	0	2	0.18
Intercalary	1	0	0	0.09
Mixed	5	0	2	0.63
Unspecified	3	0	0	0.27
Diaphragmatic hernia	7	0	38	4.07
Omphalocele	1	0	33	3.08
Gastroschisis	5	1	70	6.88
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	5	1	9	1.36
Trisomy 18	6	1	17	2.17
Down syndrome, all ages (include age unknown)	79	1	68	13.40
<20	9	1	0	nr
20-24	14	0	2	nr
25-29	8	0	1	nr
30-34	17	0	4	nr
35-39	19	0	37	nr
40-44	9	0	18	nr
45+	1	0	1	nr
unknown	3	0	5	---

nr = not reported

Cuba: RECUMAC, Previous years rates 1985 - 2008

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

	1974-1978	1979-1983	1984-1988*	1989-1993	1994-1998	1999-2003	2004-2008
Total births			**132,887**	**247,658**	**230,039**	**454,218**	**568,447**
Anencephaly			0.90	0.69	0.09	2.80	3.98
Spina bifida			5.42	3.27	2.48	3.30	5.12
Encephalocele			0.45	0.28	0.22	0.31	1.60
Microcephaly			0.53	0.48	0.39	0.29	0.60
Holoprosencephaly			0.38	0.00	0.09	0.11	0.67
Hydrocephaly			2.03	3.84	1.61	4.49	7.71
Anophthalmos			0.00	0.08	0.00	0.09	0.12
Microphthalmos			0.08	0.04	0.04	0.22	0.18
Unspecified Anophthalmos / Microphthalmos			0.00	0.00	0.00	0.00	0.07
Anotia			0.00	0.00	0.04	0.09	0.12
Microtia			0.75	0.69	0.91	0.68	0.39
Unspecified Anotia / Microtia			0.00	0.00	0.00	0.00	0.07
Transposition of great vessels			0.38	0.40	0.83	1.45	1.64
Tetralogy of Fallot			0.08	0.28	0.61	1.59	1.58
Hypoplastic left heart syndrome			0.83	0.77	0.52	0.59	1.85
Coarctation of aorta			0.08	0.04	0.17	0.29	0.53
Choanal atresia, bilateral			0.30	0.04	0.13	0.20	0.11
Cleft palate without cleft lip			1.43	1.25	1.61	1.59	1.67
Cleft lip with or without cleft palate			4.74	5.41	6.13	5.35	4.49
Oesophageal atresia / stenosis with or without fistula			0.90	1.53	1.96	2.33	2.48
Small intestine atresia / stenosis			0.98	0.61	0.74	1.19	2.22
Anorectal atresia / stenosis			1.28	1.45	1.17	1.39	1.28
Undescended testis (36 weeks of gestation or later)			5.79	2.38	4.56	2.51	2.67
Hypospadias			13.39	15.55	10.61	7.77	9.41
Epispadias			0.23	0.32	0.13	0.09	0.25
Indeterminate sex			0.23	0.16	0.17	0.35	0.40
Renal agenesis			0.68	0.32	0.35	0.66	1.06
Cystic kidney			1.05	1.25	0.52	1.61	3.41
Bladder exstrophy			0.23	0.12	0.22	0.13	0.09
Polydactyly, preaxial			0.15	0.16	0.30	0.75	0.74
Total Limb reduction defects (include unspecified)			3.16	2.54	2.48	2.44	2.27
Transverse			1.20	0.97	0.74	0.57	0.79
Preaxial			0.00	0.00	0.00	0.04	0.04
Postaxial			0.00	0.00	0.00	0.00	0.04
Intercalary			0.00	0.00	0.00	0.07	0.18
Mixed			0.00	0.00	0.00	0.20	0.44
Unspecified			1.96	1.57	1.74	1.56	0.86
Diaphragmatic hernia			1.96	1.17	1.43	1.63	2.41
Omphalocele			0.83	0.77	0.39	1.14	2.16
Gastroschisis			0.45	0.32	0.48	1.63	5.35
Unspecified Omphalocele / Gastroschisis			0.23	0.00	0.00	0.24	0.09
Prune belly sequence			0.15	0.12	0.00	0.00	0.09
Trisomy 13			0.30	0.61	0.39	0.68	1.39
Trisomy 18			0.15	0.20	0.35	0.42	1.64
Down syndrome, all ages (include age unknown)			8.73	7.67	7.04	8.72	12.12
<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

Cuba: RECUMAC

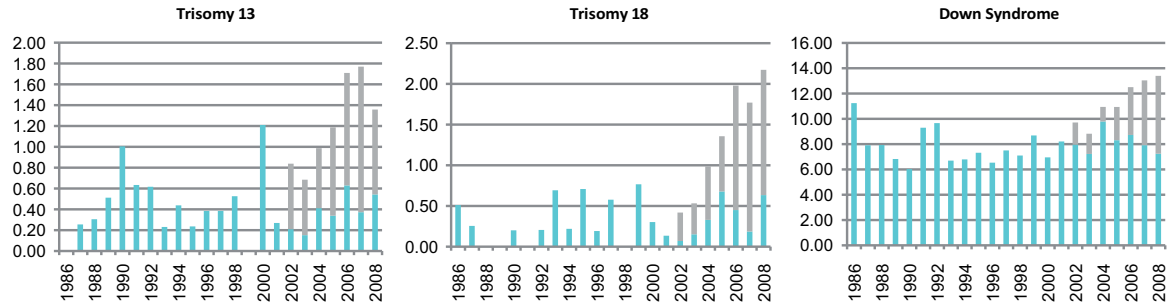
Time trends 1985-2008 (Birth prevalence rates per 10,000)

Note: L+S rates, ToP rates

Cuba: RECUMAC

Note: L+S rates, ToP rates

Cuba: RECUMAC



Note: L+S rates, ToP rates

Czech Republic

Congenital Malformations Monitoring Program of the Czech Republic

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

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

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

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

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

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

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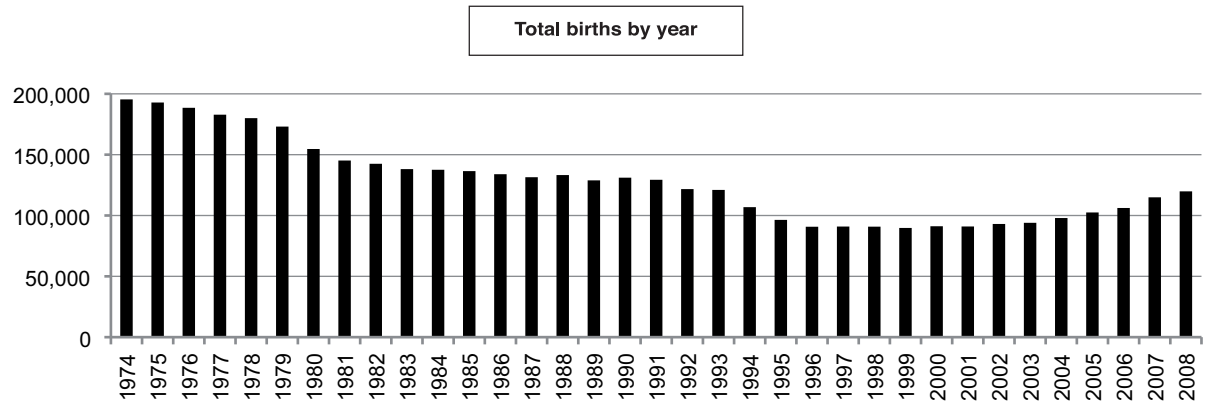
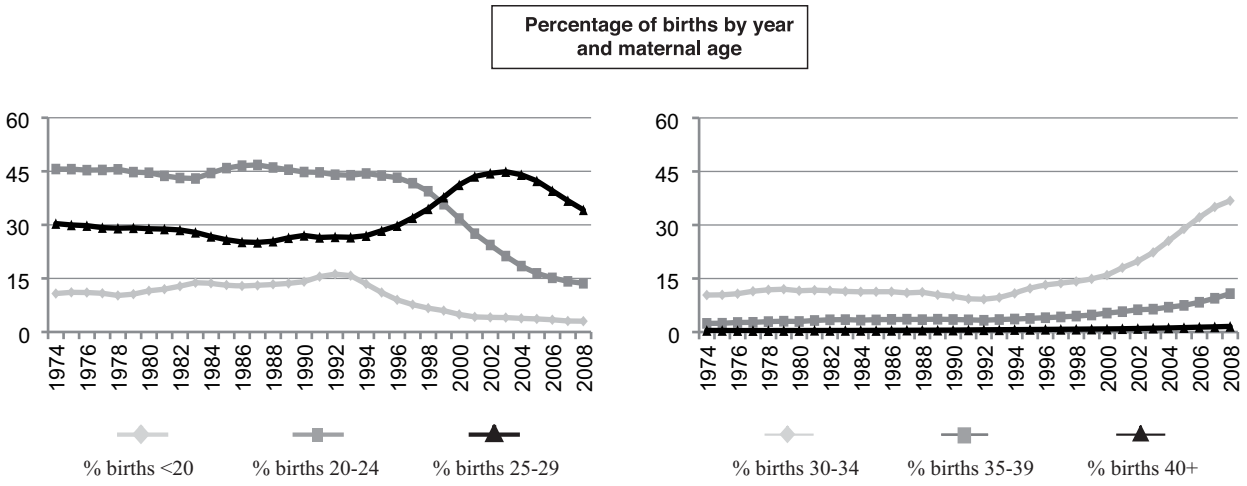
Czech Republic





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	82	93.2	Cystic kidney	43	22.1
Spina bifida	116	81.7	Limb reduction defects	34	14.9
Encephalocele	48	76.2	Diaphragmatic hernia	29	27.1
Holoprosencephaly	10	32.3	Omphalocele	67	67.7
Hydrocephaly	98	64.1	Gastroschisis	69	68.3
Hypoplastic left heart syndrome	56	58.9	Trisomy 13	61	81.3
Cleft palate without cleft lip	20	7.0	Trisomy 18	145	91.8
Cleft lip with or without cleft palate	30	8.0	Down syndrome	583	80.7
Renal agenesis	60	23.4			

Total ToPs with births defects = 2,367 (Ratio ToPs/Births: 6.94 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Czech Republic, 2008

Live births (LB)	119,570
Stillbirths (SB)	272
Total births	119,842
Number of terminations of pregnancy (ToP) for birth defects	876

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	24	2.17
Spina bifida	9	0	37	3.84
Encephalocele	2	0	14	1.34
Microcephaly	14	0	1	1.25
Holoprosencephaly	0	2	6	0.67
Hydrocephaly	25	0	38	5.26
Anophthalmos	11	0	nr	0.92
Microphthalmos	5	0	nr	0.42
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	3	0	nr	0.25
Microtia	4	0	nr	0.33
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	40	0	10	4.17
Tetralogy of Fallot	35	0	8	3.59
Hypoplastic left heart syndrome	15	0	23	3.17
Coarctation of aorta	46	0	9	4.59
Choanal atresia, bilateral	5	1	nr	0.50
Cleft palate without cleft lip	109	1	nr	9.18
Cleft lip with or without cleft palate	124	2	26	12.68
Oesophageal atresia/stenosis with or without fistula	44	0	nr	3.67
Small intestine atresia/stenosis	37	0	nr	3.09
Anorectal atresia/stenosis	61	0	nr	5.09
Undescended testis (36 weeks of gestation or later)	393	0	nr	32.79
Hypospadias	384	1	nr	32.13
Epispadias	4	0	nr	0.33
Indeterminate sex	5	0	nr	0.42
Renal agenesis	76	0	23	8.26
Cystic kidney	70	0	22	7.68
Bladder exstrophy	1	0	0	0.08
Polydactyly, preaxial	191	0	nr	15.94
Total Limb reduction defects (include unspecified)	62	1	19	6.84
Transverse	19	0	nr	1.59
Preaxial	3	0	nr	0.25
Postaxial	0	0	nr	0.00
Intercalary	1	0	nr	0.08
Mixed	nr	nr	nr	nr
Unspecified	39	1	19	4.92
Diaphragmatic hernia	26	0	11	3.09
Omphalocele	14	0	28	3.50
Gastroschisis	12	0	24	3.00
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	1	24	2.25
Trisomy 18	2	0	52	4.51
Down syndrome, all ages (include age unknown)	43	1	220	22.03
<20	1	0	0	2.76
20-24	4	0	9	7.96
25-29	8	1	34	10.49
30-34	20	0	63	18.82
35-39	6	0	80	66.68
40-44	4	0	31	190.74
45+	0	0	3	491.80
unknown	0	0	0	---

nr = not reported

Czech Republic, Previous years rates 1974 - 2008

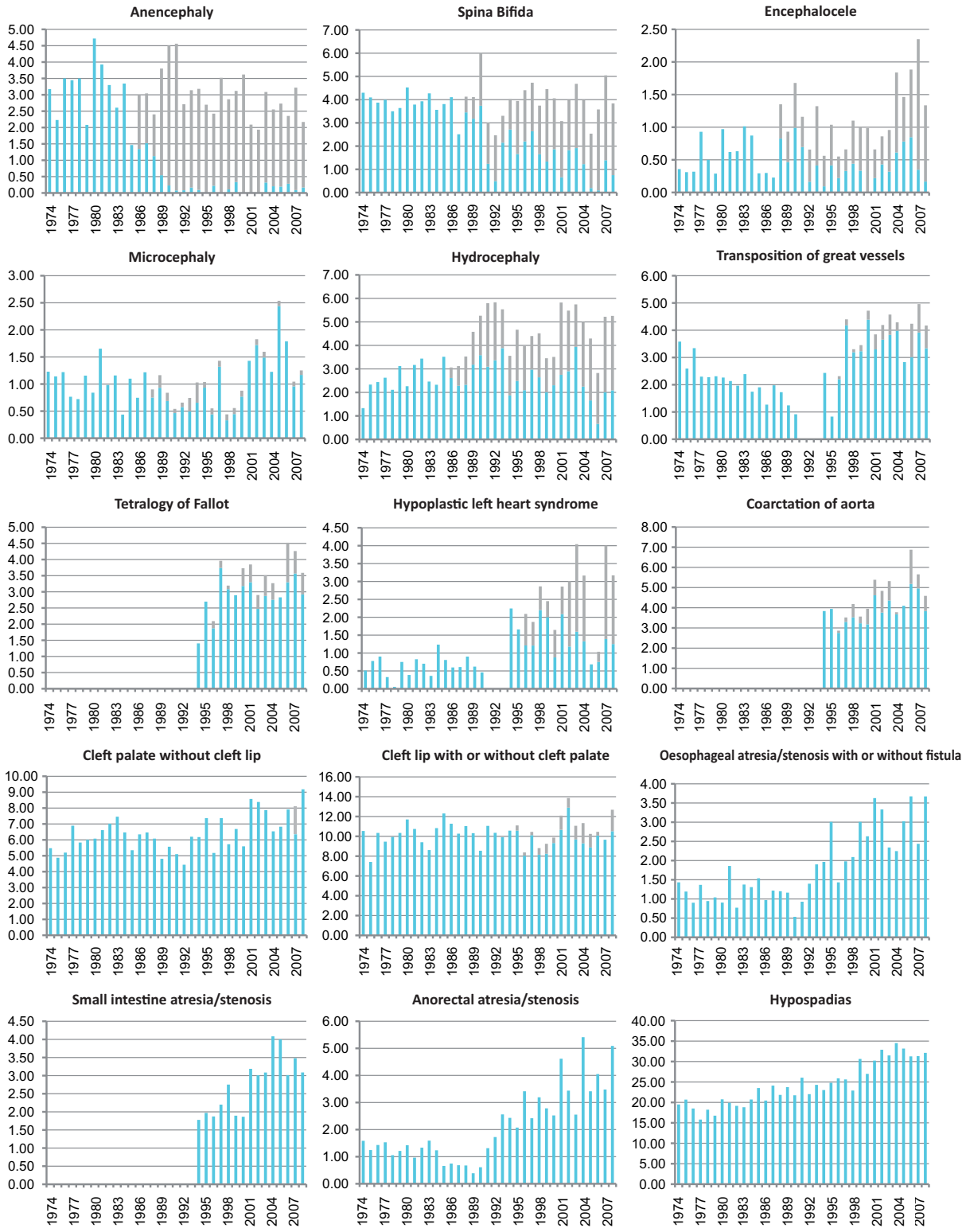
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**939,701**	**753,577**	**672,724**	**632,059**	**475,780**	**458,961**	**541,400**
Anencephaly	3.16	3.30	2.65	3.77	2.94	2.77	2.60
Spina bifida	3.96	4.02	3.63	3.81	4.16	4.05	3.82
Encephalocele	0.48	0.69	0.61	1.15	0.78	0.89	1.77
Microcephaly	1.02	1.15	0.88	0.79	0.90	1.26	1.55
Holoprosencephaly	nr	nr	nr	nr	0.14*	0.61	0.98
Hydrocephaly	2.16	2.89	3.11	5.40	4.20	4.82	4.54
Anophthalmos	nr	nr	nr	nr	0.11*	0.04	0.37*
Microphthalmos	nr	nr	nr	nr	0.22*	0.33	0.31*
Unspecified Anophthalmos / Microphthalmos	nr	nr	nr	nr	0.00*	0.00	0.17
Anotia	nr	nr	nr	nr	1.21*	0.76	0.31*
Microtia	nr	nr	nr	nr	0.11*	0.41	0.46*
Unspecified Anotia / Microtia	nr	nr	nr	nr	0.00*	5.56	0.17
Transposition of great vessels	2.83	2.22	1.72	1.08*	2.63	4.16	4.12
Tetralogy of Fallot	nr	nr	nr	nr	2.63	3.38	3.71
Hypoplastic left heart syndrome	0.52	0.61	0.83	0.54*	2.14	2.81	2.46
Coarctation of aorta	nr	nr	nr	nr	3.68	4.62	5.02
Choanal atresia, bilateral	nr	nr	nr	nr	0.36	0.15	0.43*
Cleft palate without cleft lip	5.64	6.60	6.14	5.22	6.37	7.43	7.78
Cleft lip with or without cleft palate	9.53	10.20	11.15	10.03	9.90	11.24	10.90
Oesophageal atresia / stenosis with or without fistula	1.17	1.18	1.25	1.17	2.10	2.99	3.03
Small intestine atresia / stenosis	nr	nr	nr	nr	2.10	2.61	3.51
Anorectal atresia / stenosis	1.37	1.30	0.80	1.30	2.69	3.18	4.29
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	7.31	21.31	28.83
Hypospadias	18.58	19.02	22.12	23.57	24.40	30.46	32.42
Epispadias	nr	nr	nr	nr	0.40	0.46	0.37
Indeterminate sex	nr	nr	nr	nr	0.36	0.57	0.31
Renal agenesis	1.68	1.49	1.13	1.85	2.48	4.92	7.70
Cystic kidney	2.41	2.68	2.68	2.58	3.11	5.56	6.52
Bladder exstrophy	0.17	0.11	0.06	0.00*	0.16*	0.15	0.19*
Polydactyly, preaxial	nr	nr	12.01*	12.09	13.85	13.38	14.74
Total Limb reduction defects (include unspecified)	4.41	4.67	4.77	5.57	5.09	5.66	6.54
Transverse	nr	nr	nr	nr	nr	nr	1.59*
Preaxial	nr	nr	nr	nr	nr	nr	0.25*
Postaxial	nr	nr	nr	nr	nr	nr	0.00*
Intercalary	nr	nr	nr	nr	nr	nr	0.08*
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	4.41	4.67	4.77	5.57	5.09	5.66	3.34*
Diaphragmatic hernia	2.71	2.36	2.44	1.66	2.31	2.70	2.81
Omphalocele	2.36	2.10	2.51	2.31	2.25	2.72	2.72
Gastroschisis	0.96	1.33	1.37	0.59	2.59	2.92	3.05
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.00	0.02	0.00	0.00*
Prune belly sequence	nr	nr	nr	nr	nr	0.00*	0.12*
Trisomy 13	nr	nr	nr	0.22*	0.86	1.48	2.18
Trisomy 18	nr	nr	0.38*	0.93	2.67	3.90	4.80
Down syndrome, all ages (include age unknown)	8.27	8.47	8.16	9.71	13.72	16.36	20.39
<20	5.32	3.74	5.29	4.74	5.20	8.46	4.93
20-24	5.31	5.11	4.46	3.33	7.85	8.39	8.49
25-29	8.14	7.81	7.99	5.71	9.97	10.64	10.30
30-34	12.35	9.44	8.23	9.75	18.13	20.31	18.89
35-39	34.69	30.12	28.70	35.11	55.41	59.23	66.43
40-44	114.24	127.89	60.49	137.18	247.16	186.53	204.37
45+	147.78	458.02	0.00	782.61	672.27	584.80	534.35
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

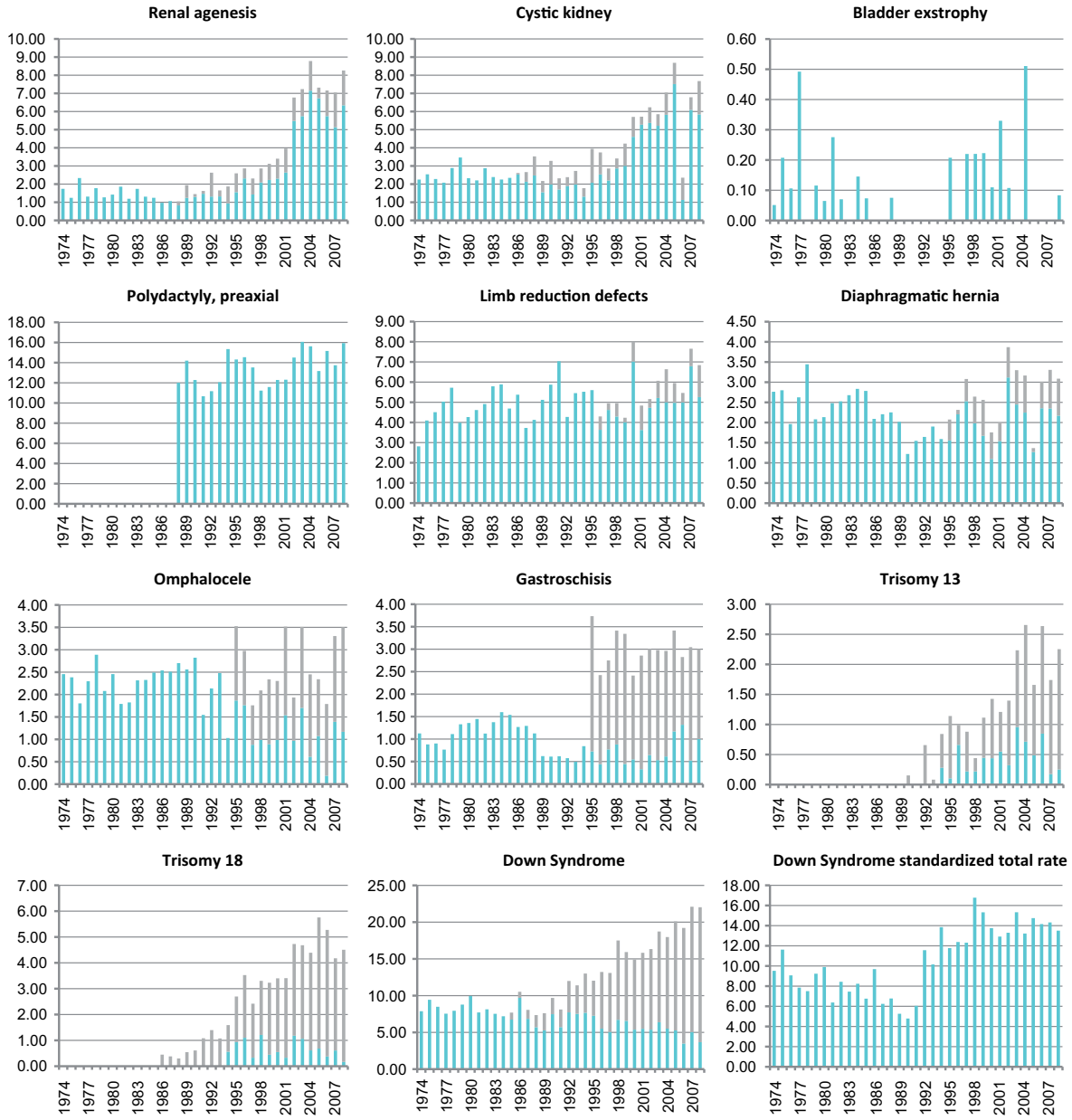
Czech Republic

Time trends 1974-2008 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

Czech Republic



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 g or more are registered. Information on malformations is principally collected up to 1 year of age, but later information is also included. Elective terminations of pregnancy for fetal anomalies and spontaneous abortions with malformations 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 malformation cases 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 malformations and their controls. In 1987-1992 only parental occupation was reported. Exposure information, like maternal occupation, medication, X-rays and diseases, etc., has been obtained since 1993. Some exposure information on all births is also available in the Medical Birth Register since 1987.

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

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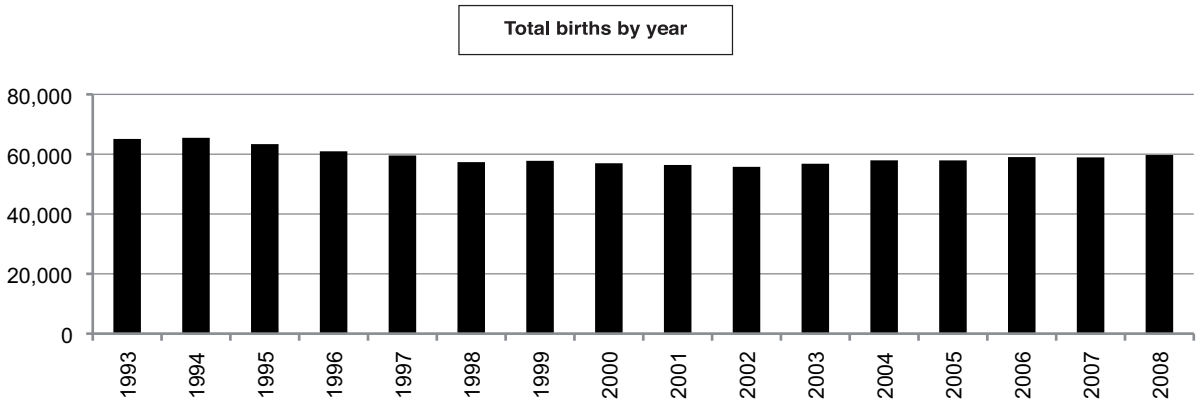
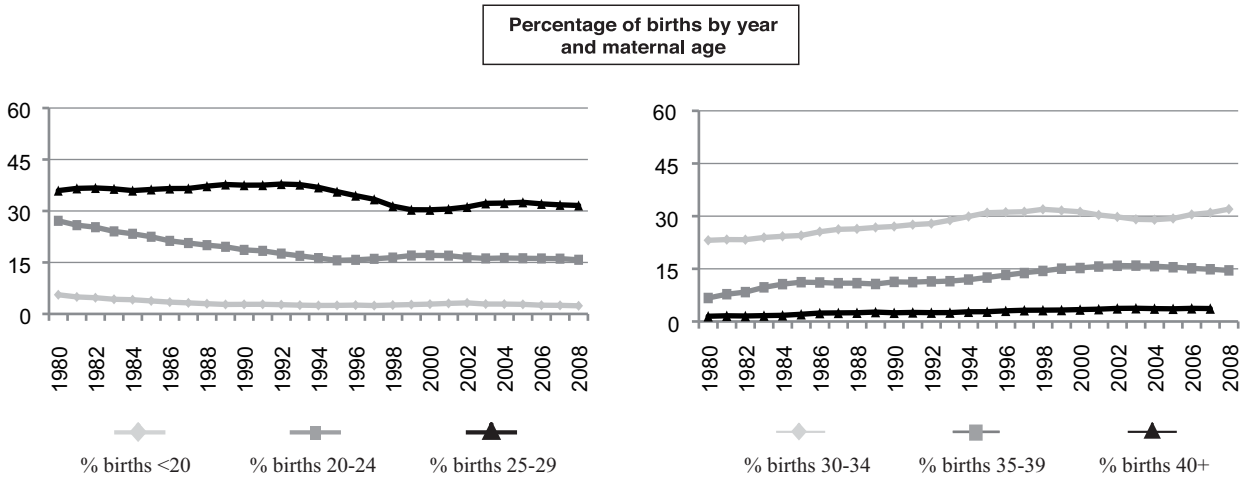
Finland





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	52	91.2	Cystic kidney	40	24.2
Spina bifida	49	59.0	Limb reduction defects	26	21.1
Encephalocele	27	79.4	Diaphragmatic hernia	24	36.9
Holoprosencephaly	29	80.6	Omphalocele	70	70.7
Hydrocephaly	31	39.2	Gastroschisis	17	29.8
Hypoplastic left heart syndrome	21	42.9	Trisomy 13	35	72.9
Cleft palate without cleft lip	17	7.1	Trisomy 18	92	80.7
Cleft lip with or without cleft palate	41	19.5	Down syndrome	295	54.0
Renal agenesis	9	50.0			

Total ToPs with births defects = 926 (Ratio ToPs/Births: 5.21 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Finland, 2008

Live births (LB)	59,530
Stillbirths (SB)	189
Total births	59,719
Number of terminations of pregnancy (ToP) for birth defects	299

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	20	3.68
Spina bifida	16	0	16	5.36
Encephalocele	1	0	13	2.34
Microcephaly	13	0	5	3.01
Holoprosencephaly	2	1	4	1.17
Hydrocephaly	15	1	11	4.52
Anophthalmos	0	0	2	0.33
Microphthalmos	6	0	1	1.17
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	22	0	0	3.68
Transposition of great vessels	25	0	3	4.69
Tetralogy of Fallot	18	0	0	3.01
Hypoplastic left heart syndrome	8	0	6	2.34
Coarctation of aorta	53	0	2	9.21
Choanal atresia, bilateral	5	0	0	0.84
Cleft palate without cleft lip	78	0	3	13.56
Cleft lip with or without cleft palate	62	0	11	12.22
Oesophageal atresia/stenosis with or without fistula	18	0	1	3.18
Small intestine atresia/stenosis	3	0	0	0.50
Anorectal atresia/stenosis	23	0	2	4.19
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	114	0	1	19.26
Epispadias	35	0	0	5.86
Indeterminate sex	6	1	2	1.51
Renal agenesis	4	2	2	1.34
Cystic kidney	48	1	8	9.54
Bladder exstrophy	2	1	0	0.50
Polydactyly, preaxial	28	0	2	5.02
Total Limb reduction defects (include unspecified)	31	1	5	6.20
Transverse	25	1	1	4.52
Preaxial	0	0	3	0.50
Postaxial	2	0	1	0.50
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	4	0	0	0.67
Diaphragmatic hernia	12	0	9	3.52
Omphalocele	13	1	23	6.20
Gastroschisis	10	1	1	2.01
Unspecified Omphalocele/Gastroschisis	1	0	5	1.00
Prune belly sequence	1	0	0	0.17
Trisomy 13	1	1	7	1.51
Trisomy 18	7	2	27	6.03
Down syndrome, all ages (include age unknown)	78	4	102	30.81
<20	1	0	0	7.07
20-24	4	1	5	10.61
25-29	15	1	8	12.71
30-34	26	2	22	26.16
35-39	23	0	36	67.87
40-44	8	0	27	167.22
45+	1	0	4	462.96
unknown	0	0	0	---

nr = not reported

Finland, Previous years rates 1993 - 2008

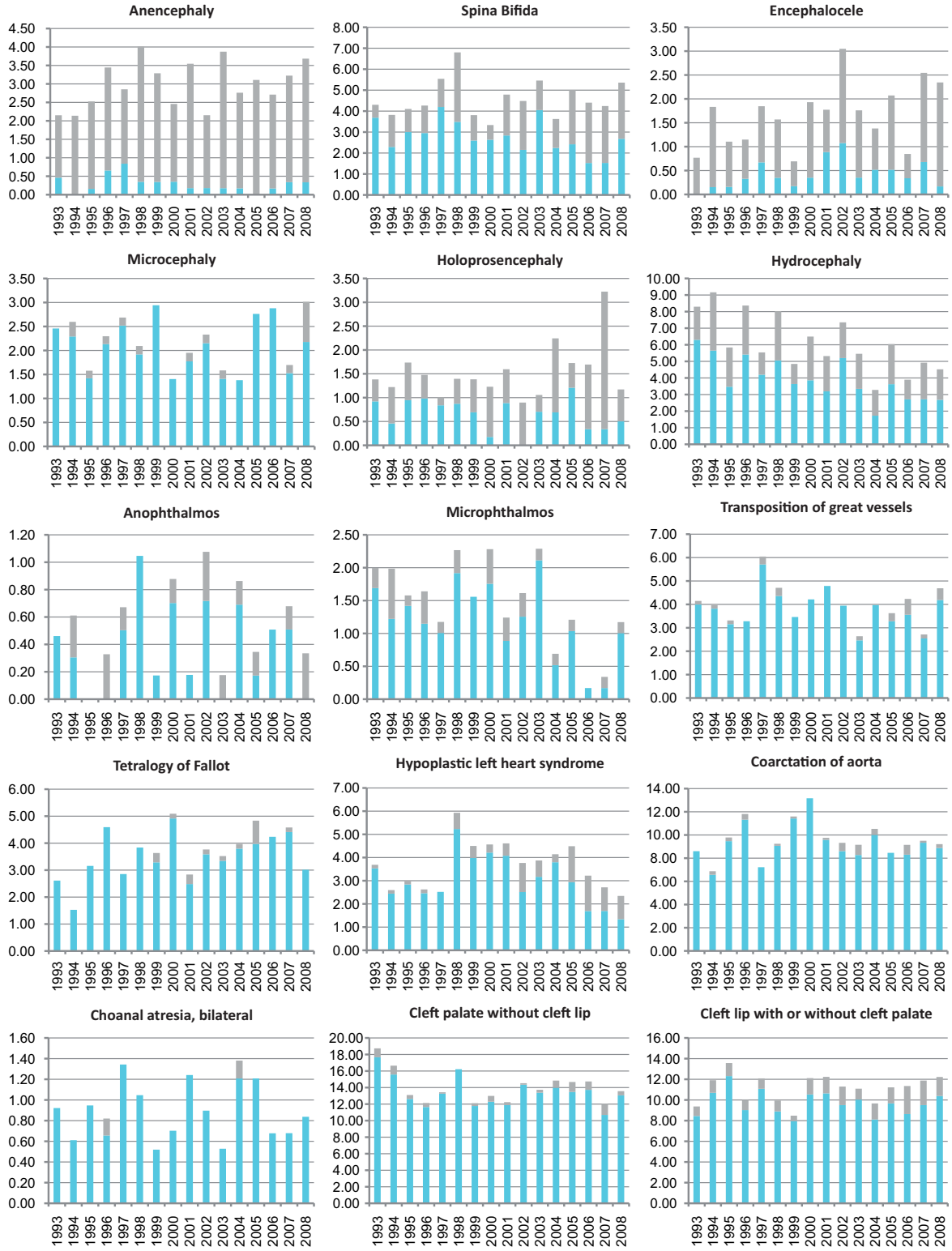
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993*	1994-1998	1999-2003	2004-2008
Total births				**65,098**	**306,727**	**283,724**	**293,557**
Anencephaly				2.15	2.97	3.07	3.10
Spina bifida				4.30	4.86	4.37	4.53
Encephalocele				0.77	1.50	1.83	1.84
Microcephaly				2.46	2.25	2.04	2.35
Holoprosencephaly				1.38	1.37	1.23	2.01
Hydrocephaly				8.30	7.40	5.89	4.53
Anophthalmos				0.46	0.52	0.49	0.55
Microphthalmos				2.00	1.73	1.80	0.72
Unspecified Anophthalmos / Microphthalmos				0.00	0.00	0.00	0.00
Anotia				nr	nr	nr	nr
Microtia				nr	nr	nr	nr
Unspecified Anotia / Microtia				4.30	5.02	4.26	4.22
Transposition of great vessels				4.15	4.24	3.81	3.85
Tetralogy of Fallot				2.61	3.16	3.77	4.12
Hypoplastic left heart syndrome				3.69	3.29	4.26	3.37
Coarctation of aorta				8.60	8.97	10.61	9.37
Choanal atresia, bilateral				0.92	0.95	0.78	0.95
Cleft palate without cleft lip				18.74	14.31	13.11	13.97
Cleft lip with or without cleft palate				9.37	11.54	11.03	11.28
Oesophageal atresia / stenosis with or without fistula				2.46	3.78	3.81	3.85
Small intestine atresia / stenosis				1.23	1.14	0.99	1.23
Anorectal atresia / stenosis				5.68	5.31	4.83	5.59
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				3.99	3.49	3.35	3.71
Epispadias				0.15	0.29	0.35	0.37
Indeterminate sex				0.92	0.88	1.94	1.53
Renal agenesis				1.54	2.09	1.27	1.29
Cystic kidney				5.68	6.29	7.58	8.75
Bladder exstrophy				0.61	0.46	0.74	0.68
Polydactyly, preaxial				5.38	4.30	4.23	4.84
Total Limb reduction defects (include unspecified)				6.76	7.30	7.44	7.02
Transverse				3.38	4.40	3.49	4.12
Preaxial				2.15	1.73	2.54	1.29
Postaxial				0.15	0.36	0.53	0.51
Intercalary				0.46	0.36	0.39	0.34
Mixed				0.46	0.36	0.21	0.34
Unspecified				0.15	0.10	0.28	0.41
Diaphragmatic hernia				2.92	2.48	2.71	3.54
Omphalocele				3.99	3.85	4.93	5.48
Gastroschisis				1.69	2.22	3.24	3.10
Unspecified Omphalocele / Gastroschisis				0.31	0.23	0.32	0.55
Prune belly sequence				0.31	0.33	0.21	0.20
Trisomy 13				1.69	2.38	1.90	2.38
Trisomy 18				5.22	5.64	6.56	6.61
Down syndrome, all ages (include age unknown)				21.81	23.25	24.35	29.53
<20				12.03	12.98	8.37	9.13
20-24				7.26	6.51	7.37	9.72
25-29				9.78	11.45	9.80	12.86
30-34				17.58	18.18	16.22	21.53
35-39				58.90	54.81	55.35	61.38
40-44				186.62	171.50	172.62	201.30
45+				235.29	292.28	398.41	386.10
unknown				---	---	---	---

nr = not reported
* data include only 1 year

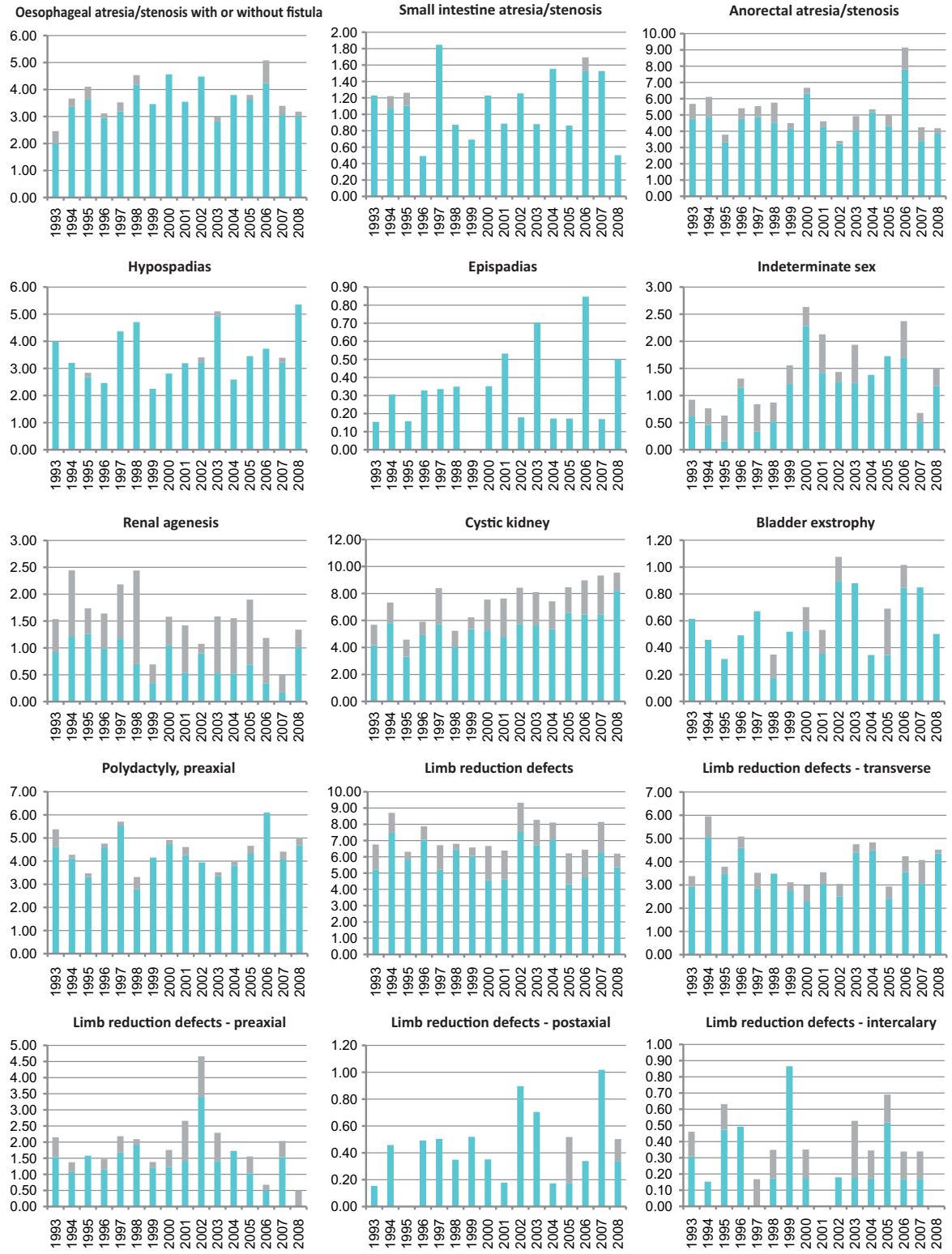
Finland

Time trends 1993-2008 (Birth prevalence rates per 10,000)



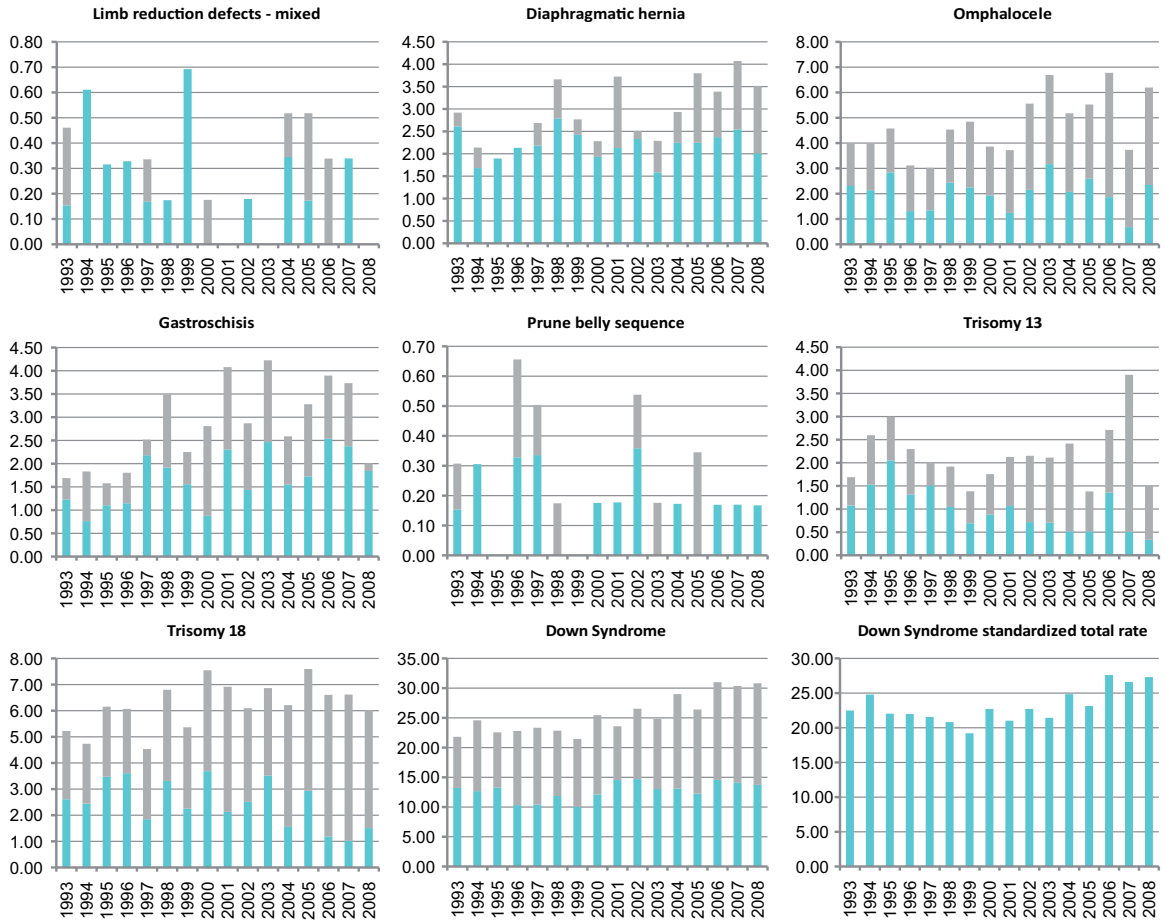
Note: L+S rates, ToP rates

Finland



Note: L+S rates, ToP rates

Finland



Note: L+S rates, ToP rates

France: Paris

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:
Reporting is volontary. The registry is part of a research unit of INSERM (National Institute of Health and Medical Research). The registry has been officially recognized by the French National Comity of Registries, and is renewed for four years (2001-2004) and 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 delivery units, pediatric departments, cytogenetic laboratories, pathology departments. Terminations of pregnancy are included. Case information is also received from the health certificates of the first week.

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

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

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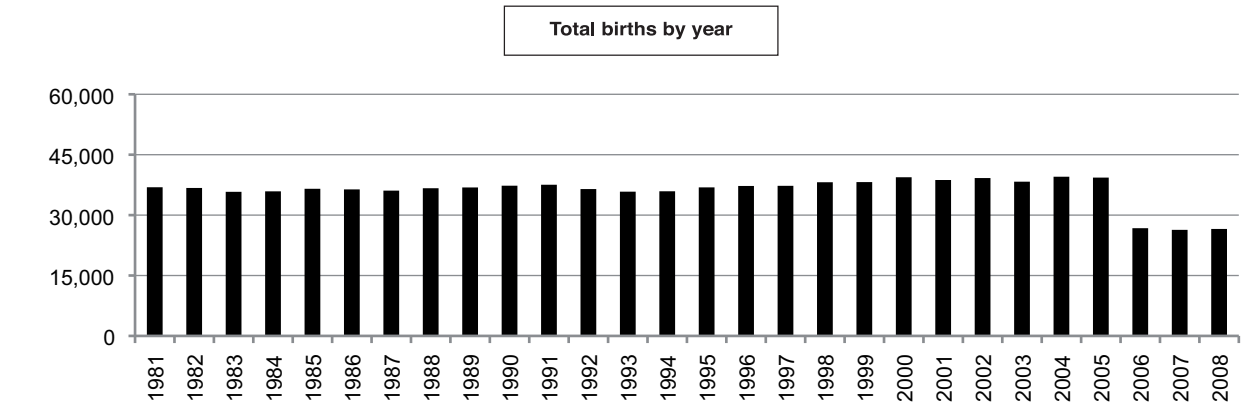
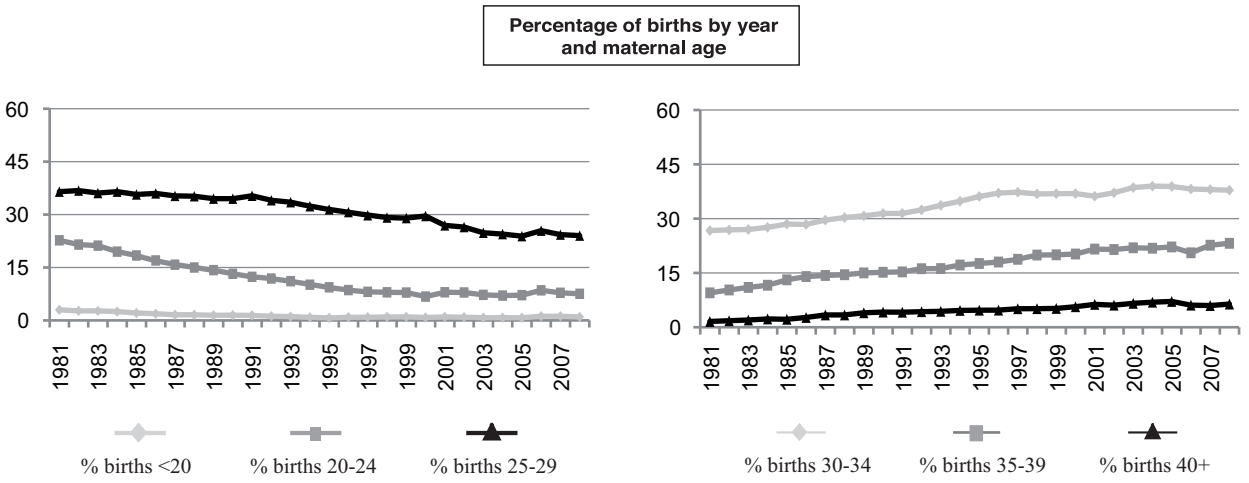




Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	33	97.1	Cystic kidney	23	27.1
Spina bifida	33	82.5	Limb reduction defects	27	50.9
Encephalocele	15	65.2	Diaphragmatic hernia	7	31.8
Holoprosencephaly	23	95.8	Omphalocele	29	64.4
Hydrocephaly	54	40.0	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	16	55.2	Trisomy 13	34	89.5
Cleft palate without cleft lip	8	15.1	Trisomy 18	105	92.9
Cleft lip with or without cleft palate	25	32.5	Down syndrome	280	80.7
Renal agenesis	16	100.0			

Total ToPs with births defects = 856 (Ratio ToPs/Births: 10.75 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Paris, 2008

Live births (LB)	26,224
Stillbirths (SB)	339
Total births	26,563
Number of terminations of pregnancy (ToP) for birth defects	275

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	16	6.40
Spina bifida	1	0	11	4.52
Encephalocele	0	0	3	1.13
Microcephaly	2	0	3	1.88
Holoprosencephaly	0	0	9	3.39
Hydrocephaly	29	0	21	18.82
Anophthalmos	1	0	0	0.38
Microphthalmos	1	0	1	0.75
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	3	0	3	2.26
Microtia	1	0	1	0.75
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	9	0	1	3.76
Tetralogy of Fallot	10	1	2	4.89
Hypoplastic left heart syndrome	3	1	3	2.64
Coarctation of aorta	9	0	2	4.14
Choanal atresia, bilateral	1	0	0	0.38
Cleft palate without cleft lip	15	0	2	6.40
Cleft lip with or without cleft palate	13	0	11	9.04
Oesophageal atresia/stenosis with or without fistula	8	0	3	4.14
Small intestine atresia/stenosis	4	0	0	1.51
Anorectal atresia/stenosis	3	0	1	1.51
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	35	0	0	13.18
Epispadias	1	0	0	0.38
Indeterminate sex	0	0	1	0.38
Renal agenesis	0	0	4	1.51
Cystic kidney	20	0	7	10.16
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	5	0	0	1.88
Total Limb reduction defects (include unspecified)	11	0	5	6.02
Transverse	6	0	3	3.39
Preaxial	3	0	1	1.51
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.38
Mixed	0	0	0	0.00
Unspecified	1	0	1	0.75
Diaphragmatic hernia	3	0	3	2.26
Omphalocele	2	0	11	4.89
Gastroschisis	4	1	0	1.88
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	10	4.14
Trisomy 18	1	1	36	14.31
Down syndrome, all ages (include age unknown)	23	2	81	39.91
<20	0	0	0	0.00
20-24	0	0	1	4.99
25-29	2	0	5	10.96
30-34	2	0	19	20.89
35-39	8	0	27	56.83
40-44	9	2	27	242.35
45+	2	0	2	303.03
unknown	0	0	0	---

nr = not reported

France: Paris, Previous years rates 1981 - 2008

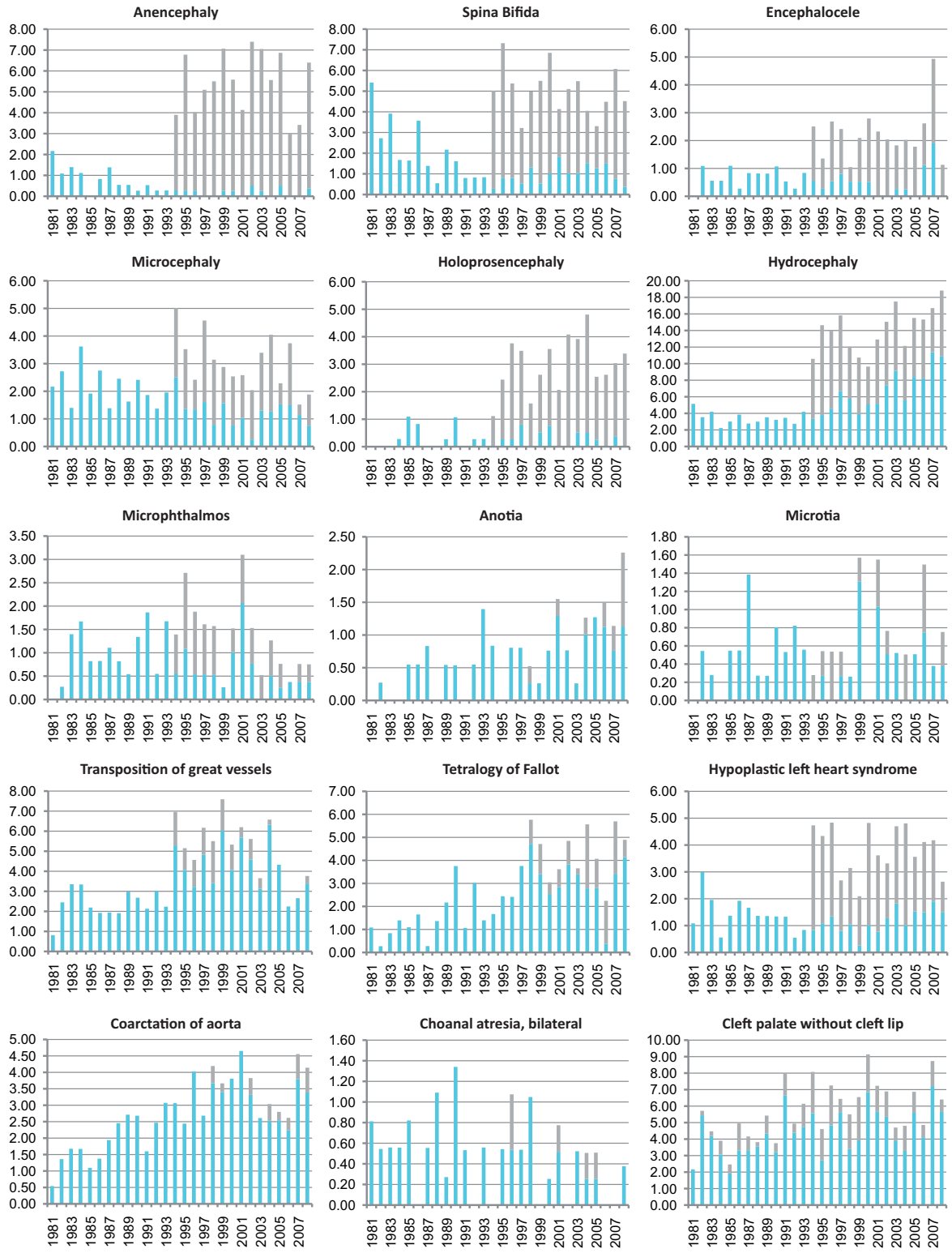
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**109,441**	**181,574**	**183,997**	**185,471**	**193,818**	**158,499**	
Anencephaly	1.55	0.77	0.38	5.07	6.24	5.24	
Spina bifida	4.02	1.76	1.25	5.18	5.42	4.35	
Encephalocele	0.55	0.72	0.71	1.99	2.22	2.40	
Microcephaly	2.10	2.42	1.85	3.72	2.68	2.78	
Holoprosencephaly	0.00	0.44	0.38	2.48	3.25	3.34	
Hydrocephaly	4.29	2.97	3.42	13.43	13.16	15.39	
Anophthalmos	0.27	0.11	0.38	0.32	0.21	0.32	
Microphthalmos	0.55	1.05	1.20	1.83	1.39	0.82	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	0.09	0.39	0.60	0.59	0.72	1.45	
Microtia	0.27	0.55	0.60	0.43	0.88	0.69	
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	2.19	2.26	2.61	5.66	5.68	4.16	
Tetralogy of Fallot	0.73	1.16	2.28	3.24	3.97	4.54	
Hypoplastic left heart syndrome	2.01	1.38	1.09	3.94	3.71	3.91	
Coarctation of aorta	1.19	1.71	2.50	3.29	3.71	3.34	
Choanal atresia, bilateral	0.64	0.61	0.54	0.65	0.31	0.32	
Cleft palate without cleft lip	4.11	3.86	5.65	6.36	6.91	6.25	
Cleft lip with or without cleft palate	6.40	6.99	8.97	9.97	7.95	8.83	
Oesophageal atresia / stenosis with or without fistula	2.10	2.37	3.59	3.77	4.39	3.66	
Small intestine atresia / stenosis	0.18	0.94	1.52	2.48	2.94	3.47	
Anorectal atresia / stenosis	3.20	2.26	2.93	3.61	3.66	3.09	
Undescended testis (36 weeks of gestation or later)	7.86	11.84	11.90	8.14	6.24*	0.00*	
Hypospadias	10.96	9.75	14.40	12.19	12.95	15.46	
Epispadias	0.00	0.61	0.49	0.43	0.26	0.69	
Indeterminate sex	1.92	0.94	1.30	1.35	1.34	1.32	
Renal agenesis	0.91	1.16	0.49	3.50	2.58	2.90	
Cystic kidney	1.01	3.30	3.70	9.06	10.89	9.91	
Bladder exstrophy	0.27	0.33	0.27	0.92	0.36	0.57	
Polydactyly, preaxial	0.46	0.94	1.36	2.37	1.55	1.83	
Total Limb reduction defects (include unspecified)	nr	nr	nr	5.88*	8.77	6.37	
Transverse	nr	nr	nr	2.14*	5.06	3.47	
Preaxial	nr	nr	nr	0.53*	1.60	1.32	
Postaxial	nr	nr	nr	0.33*	0.77	0.44	
Intercalary	nr	nr	nr	0.47*	0.52	0.32	
Mixed	nr	nr	nr	0.20*	0.62	0.50	
Unspecified	nr	nr	nr	0.00*	0.21	0.32	
Diaphragmatic hernia	2.10	2.86	2.88	5.61	5.31	3.97	
Omphalocele	1.55	1.82	1.74	4.58	6.24	5.68	
Gastroschisis	0.18	0.72	2.01	2.53	3.41	1.96	
Unspecified Omphalocele / Gastroschisis	0.18	0.55	0.22	0.81	1.08	0.95	
Prune belly sequence	0.00	0.22	0.00	0.16	0.10	0.19	
Trisomy 13	0.46	0.44	0.60	3.07	4.54	4.48	
Trisomy 18	1.46	1.05	1.09	7.76	11.61	14.26	
Down syndrome, all ages (include age unknown)	11.24	12.12	15.00	33.48	37.15	43.53	
<20	9.78	14.20	8.20	6.20	17.23	6.73	
20-24	6.70	6.43	6.92	14.06	9.56	13.40	
25-29	6.76	6.32	7.74	13.36	13.57	16.56	
30-34	10.54	12.58	13.95	20.57	20.42	24.60	
35-39	23.16	27.73	27.58	58.26	60.55	62.33	
40-44	53.79	33.15	55.46	194.07	189.14	219.96	
45+	363.64	76.92	143.27	373.83	336.70	360.11	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

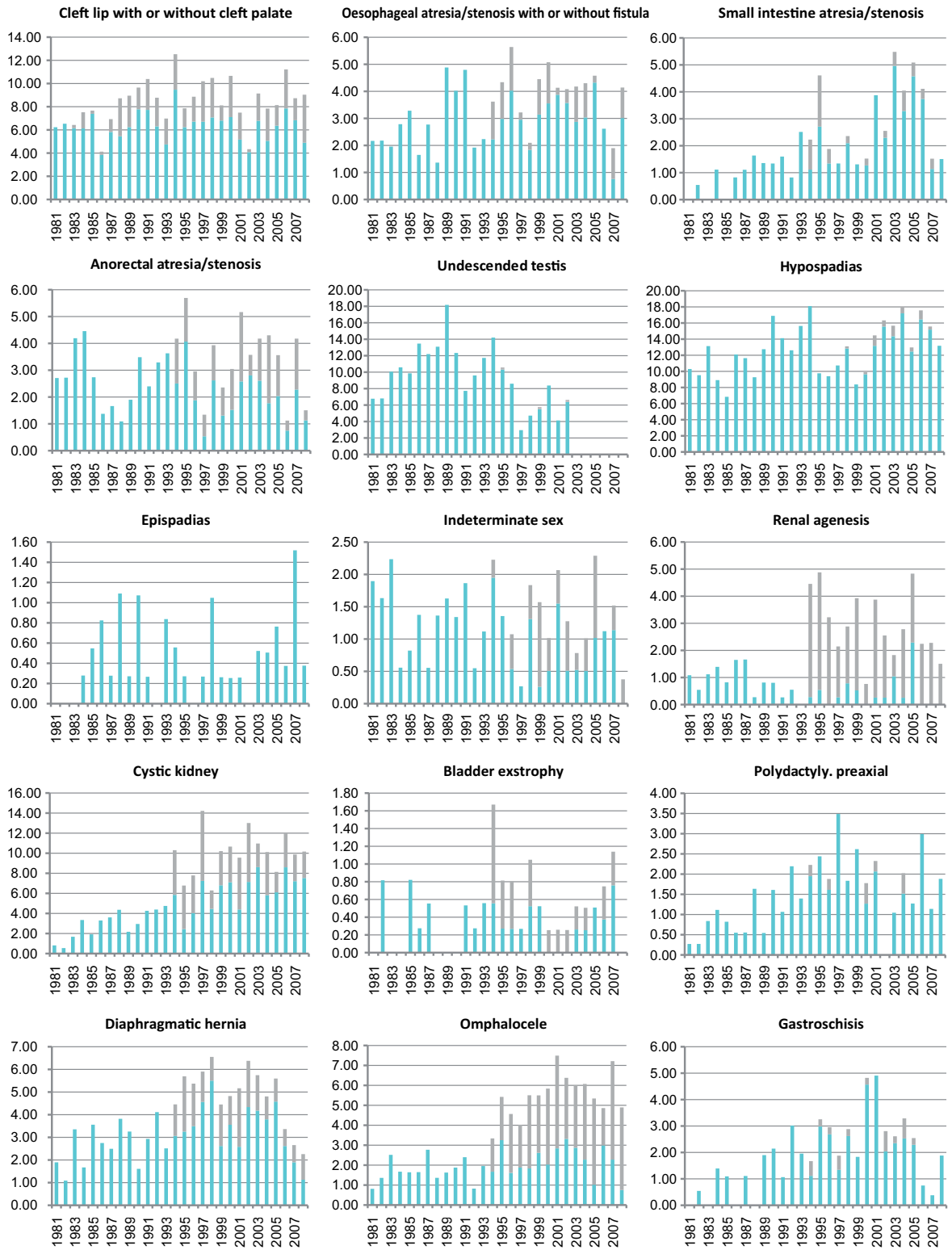
France: Paris

Time trends 1981-2008 (Birth prevalence rates per 10,000)



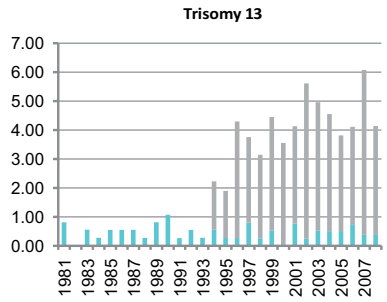
Note: L+S rates, ToP rates

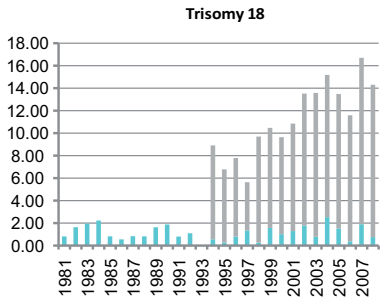
France: Paris

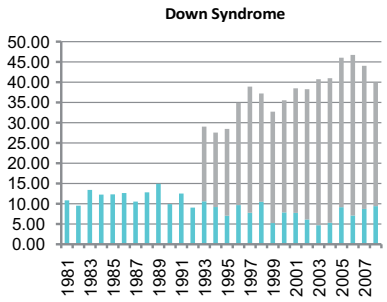


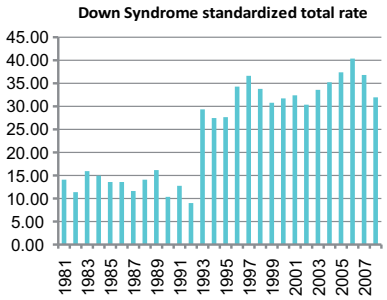
Note: L+S rates, ToP rates

France: Paris









Note: L+S rates, ToP rates

France: REMERA

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

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

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

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

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

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

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

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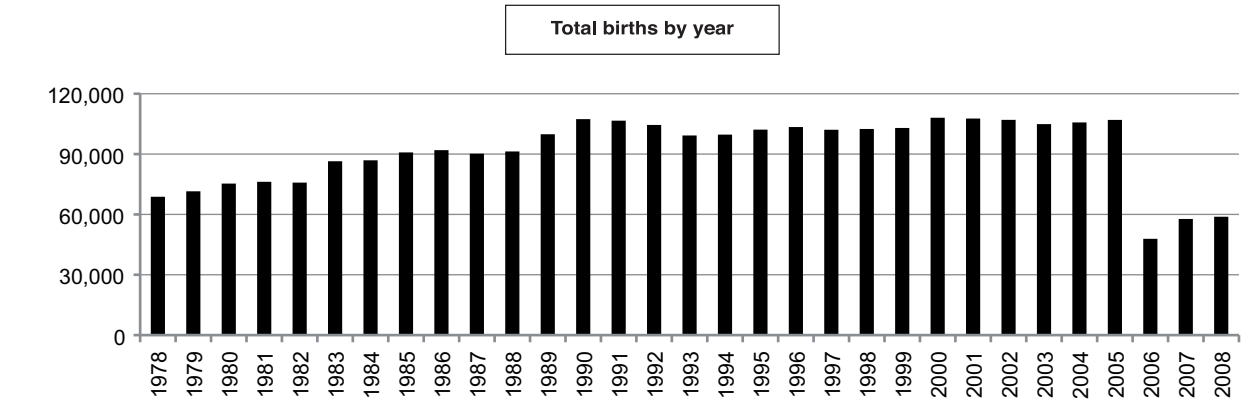
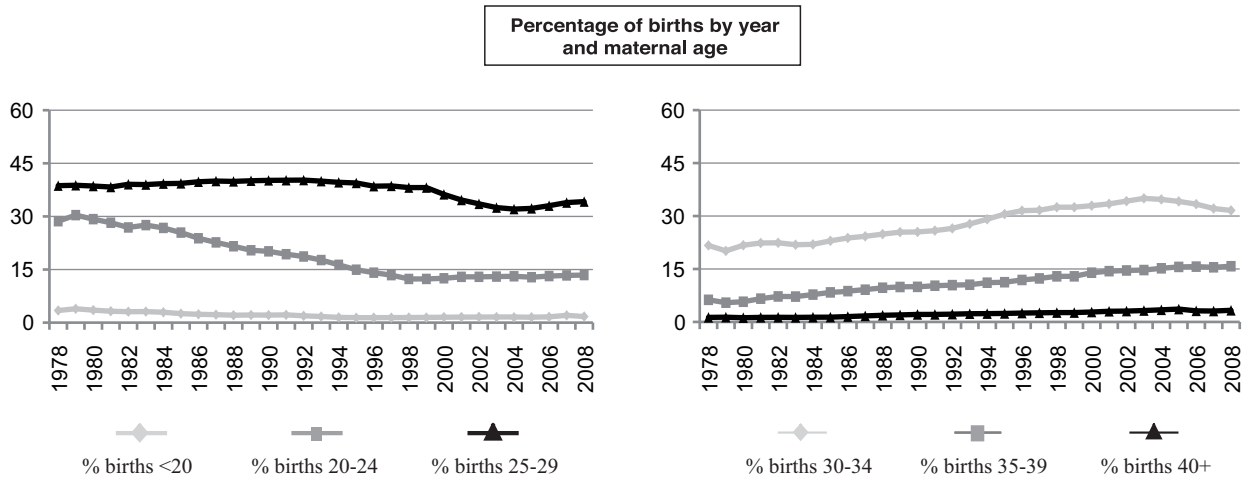
France: REMERA





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	58	92.1	Cystic kidney	57	43.8
Spina bifida	91	80.5	Limb reduction defects	54	50.0
Encephalocele	14	77.8	Diaphragmatic hernia	16	27.6
Holoprosencephaly	36	90.0	Omphalocele	39	63.9
Hydrocephaly	75	61.5	Gastroschisis	5	16.1
Hypoplastic left heart syndrome	48	55.8	Trisomy 13	52	94.5
Cleft palate without cleft lip	16	20.8	Trisomy 18	99	90.8
Cleft lip with or without cleft palate	45	28.1	Down syndrome	361	78.6
Renal agenesis	32	35.6			

Total ToPs with births defects = 1,233 (Ratio ToPs/Births: 7.50 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: REMERA, 2008

Live births (LB)	58,279
Stillbirths (SB)	574
Total births	58,853
Number of terminations of pregnancy (ToP) for birth defects	447

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	1	21	4.08
Spina bifida	6	0	23	4.93
Encephalocele	0	0	4	0.68
Microcephaly	4	0	10	2.38
Holoprosencephaly	1	0	18	3.23
Hydrocephaly	17	3	36	9.52
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	6	1.19
Unspecified Anophthalmos/Microphthalmos	1	0	6	1.19
Anotia	1	0	0	0.17
Microtia	4	0	3	1.19
Unspecified Anotia/Microtia	4	0	3	1.19
Transposition of great vessels	16	0	8	4.08
Tetralogy of Fallot	16	1	5	3.74
Hypoplastic left heart syndrome	13	1	11	4.25
Coarctation of aorta	14	0	1	2.55
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	19	0	5	4.08
Cleft lip with or without cleft palate	37	1	22	10.19
Oesophageal atresia/stenosis with or without fistula	13	0	5	3.06
Small intestine atresia/stenosis	10	0	1	1.87
Anorectal atresia/stenosis	2	0	0	0.34
Undescended testis (36 weeks of gestation or later)	3	0	0	0.51
Hypospadias	66	1	2	11.72
Epispadias	0	0	0	0.00
Indeterminate sex	2	1	1	0.68
Renal agenesis	20	0	12	5.44
Cystic kidney	20	0	25	7.65
Bladder exstrophy	1	0	1	0.34
Polydactyly, preaxial	60	0	16	12.91
Total Limb reduction defects (include unspecified)	21	2	13	6.12
Transverse	15	2	6	3.91
Preaxial	1	0	0	0.17
Postaxial	4	0	1	0.85
Intercalary	0	0	1	0.17
Mixed	1	0	1	0.34
Unspecified	0	0	4	0.68
Diaphragmatic hernia	12	1	3	2.72
Omphalocele	5	0	16	3.57
Gastroschisis	11	0	1	2.04
Unspecified Omphalocele/Gastroschisis	16	0	24	6.80
Prune belly sequence	0	0	1	0.17
Trisomy 13	0	0	24	4.08
Trisomy 18	1	0	48	8.33
Down syndrome, all ages (include age unknown)	33	2	131	28.21
<20	1	0	0	9.83
20-24	0	0	2	2.53
25-29	4	0	20	11.93
30-34	7	0	29	19.37
35-39	9	1	45	59.24
40-44	6	1	33	215.29
45+	0	0	2	253.16
unknown	6	0	0	---

France: REMERA, Previous years rates 1978 - 2008

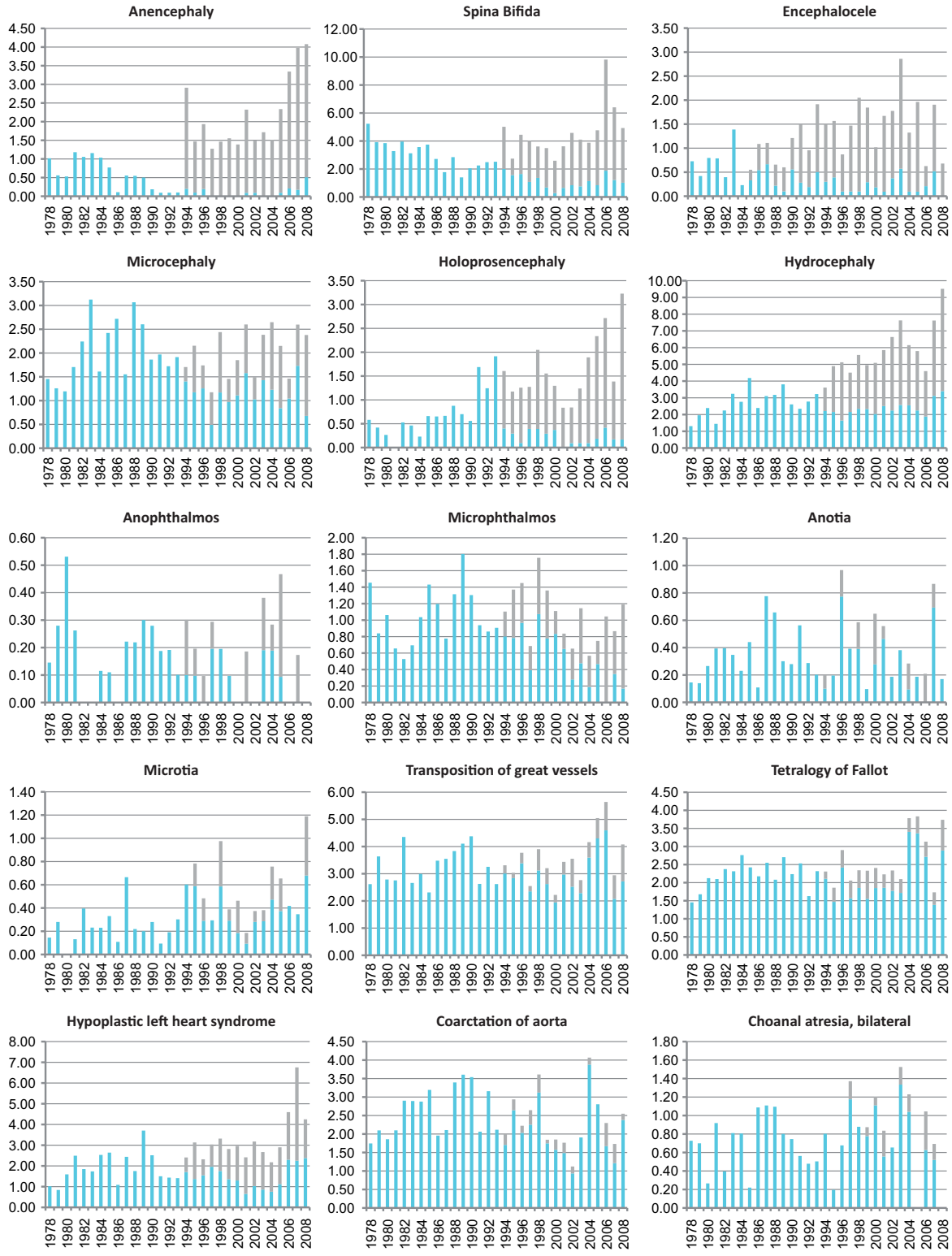
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978*	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**68,778**	**385,294**	**451,173**	**517,564**	**509,840**	**530,612**	**377,187**
Anencephaly	1.02	0.91	0.60	0.19	1.80	1.70	2.76
Spina bifida	5.23	3.61	2.93	2.14	3.96	3.68	5.43
Encephalocele	0.73	0.78	0.73	1.24	1.49	1.83	1.41
Microcephaly	1.45	1.95	2.28	2.01	1.84	1.96	2.31
Holoprosencephaly	0.58	0.34	0.62	1.22	1.47	1.15	2.25
Hydrocephaly	1.31	2.28	3.13	2.94	4.75	6.03	6.60
Anophthalmos	0.15	0.21	0.13	0.21	0.22	0.13	0.24
Microphthalmos	1.45	0.75	1.15	1.16	1.27	1.02	0.82
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.19
Anotia	0.15	0.31	0.44	0.33	0.47	0.38	0.32
Microtia	0.15	0.21	0.31	0.21	0.63	0.36	0.69
Unspecified Anotia / Microtia	0.29	0.52	0.75	0.54	0.94	0.58	0.19
Transposition of great vessels	2.62	3.22	3.24	3.40	3.31	3.03	4.40
Tetralogy of Fallot	1.45	2.13	2.39	2.28	2.29	2.28	3.39
Hypoplastic left heart syndrome	1.02	1.71	2.08	2.11	2.84	2.81	3.71
Coarctation of aorta	1.74	2.39	2.70	2.90	2.69	1.70	2.89
Choanal atresia, bilateral	0.73	0.62	0.86	0.62	0.78	1.02	0.58
Cleft palate without cleft lip	4.51	4.52	4.94	5.14	6.96	5.69	4.85
Cleft lip with or without cleft palate	7.42	6.75	6.10	6.78	8.20	7.11	8.48
Oesophageal atresia / stenosis with or without fistula	1.16	2.18	2.79	2.92	3.28	2.85	2.76
Small intestine atresia / stenosis	2.33	1.19	1.93	1.82	2.41	2.75	2.36
Anorectal atresia / stenosis	2.47	2.39	3.44	2.92	3.90	3.77	1.99
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	0.43*
Hypospadias	nr	6.41	8.13	10.01	10.81	12.34	11.32
Epispadias	0.29	0.16	0.22	0.25	0.20	0.19	0.21
Indeterminate sex	0.73	0.75	0.73	0.66	0.76	0.47	0.87
Renal agenesis	0.29	0.75	0.64	0.46	1.47	1.43	2.94
Cystic kidney	0.00	1.06	1.99	2.98	4.55	4.66	6.04
Bladder exstrophy	0.29	0.13	0.35	0.31	0.37	0.30	0.40
Polydactyly, preaxial	0.87	0.80	1.15	1.70	2.29	1.70	5.28
Total Limb reduction defects (include unspecified)	3.63	4.70	3.99	4.33	5.43	4.45	5.81
Transverse	2.18	2.31	2.13	2.57	2.53	2.19	2.92
Preaxial	0.44	0.73	0.71	0.56	0.71	1.04	1.19
Postaxial	0.44	0.23	0.29	0.50	0.33	0.45	0.58
Intercalary	0.15	0.60	0.42	0.46	0.47	0.34	0.50
Mixed	0.29	0.67	0.42	0.23	0.27	0.34	0.48
Unspecified	0.15	0.16	0.02	0.00	1.12	0.09	0.14*
Diaphragmatic hernia	2.62	2.49	2.53	2.34	3.24	2.53	3.61
Omphalocele	1.02	1.04	1.20	1.16	2.39	2.24	3.21
Gastroschisis	0.15	0.70	0.89	1.18	1.24	1.38	1.75
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.00	0.04	0.08	1.81*
Prune belly sequence	0.29	0.18	0.22	0.44	0.61	0.19	0.21
Trisomy 13	0.29	0.55	0.75	1.20	1.49	1.88	2.70
Trisomy 18	0.87	0.86	1.62	2.53	3.67	4.30	6.12
Down syndrome, all ages (include age unknown)	13.96	10.80	11.19	11.98	19.69	20.66	25.32
<20	8.47	6.18	5.47	4.76	9.63	7.26	8.04
20-24	8.12	7.04	5.07	6.52	7.31	7.98	7.29
25-29	6.01	5.16	7.15	5.44	7.92	8.56	8.32
30-34	11.40	10.87	10.15	8.70	14.33	12.56	17.12
35-39	32.50	26.88	26.37	24.22	45.31	43.81	55.67
40-44	173.27	75.01	57.54	65.09	154.89	134.76	159.45
45+	0.00	141.84	160.18	215.44	287.08	210.67	264.08
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

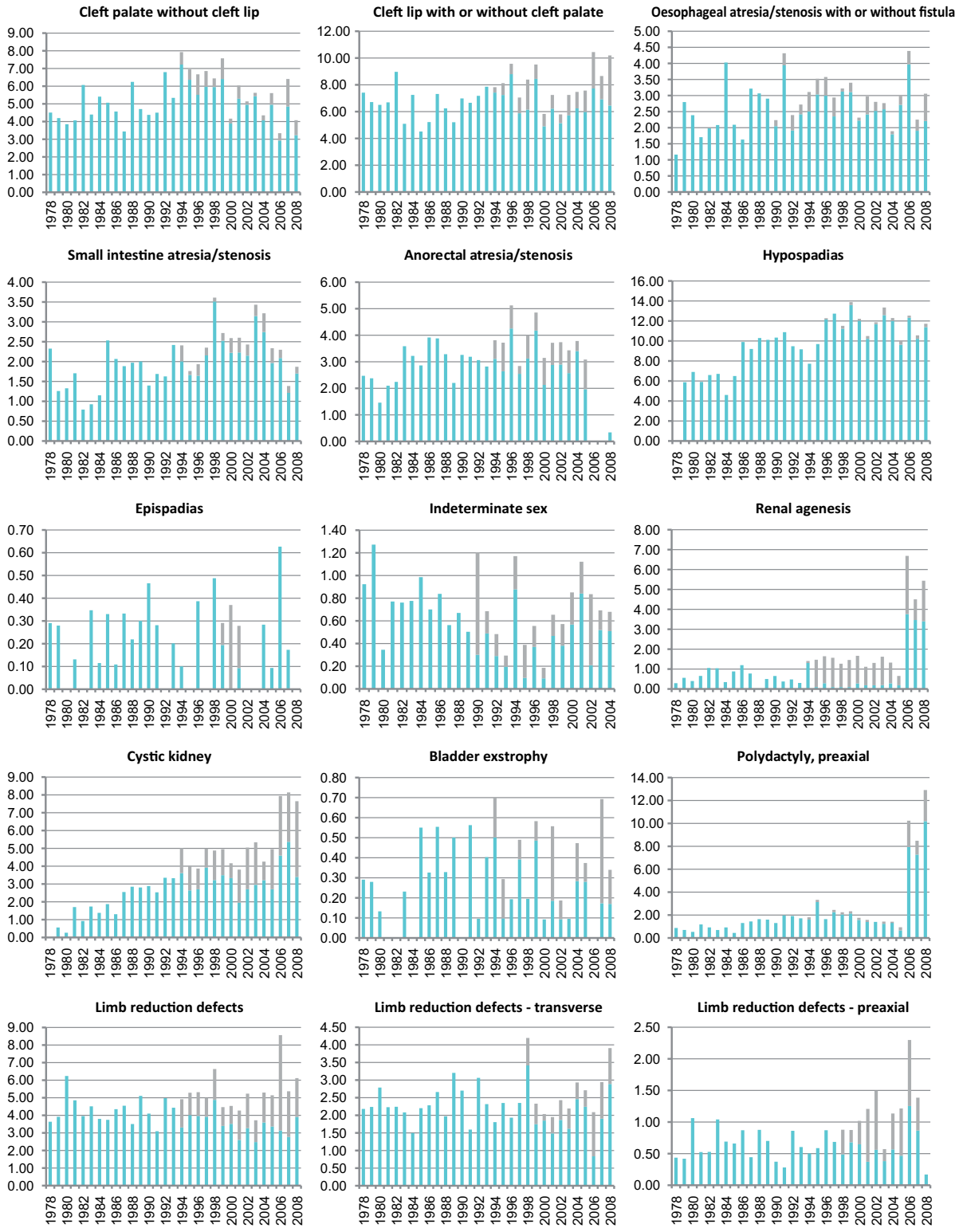
France: REMERA

Time trends 1978-2008 (Birth prevalence rates per 10,000)



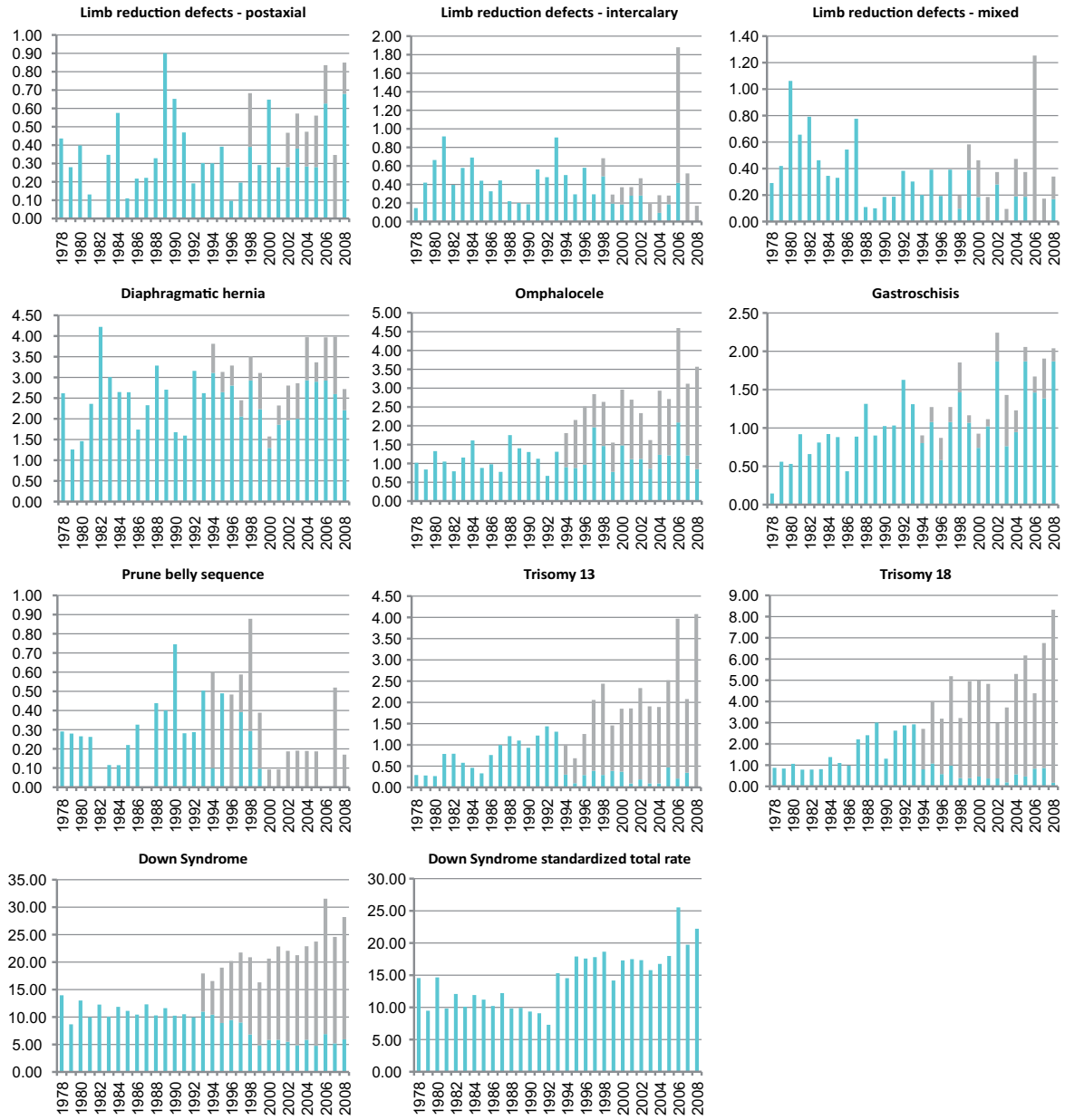
Note: L+S rates, ToP rates

France: REMERA



Note: L+S rates, ToP rates

France: REMERA



Note: L+S rates, ToP rates

Germany: Saxony-Anhalt
Malformation Monitoring Saxony-Anhalt

History:
Since 1980 in the city of Magdeburg all live- and stillbirths, abortions after the 16th week of gestation (spontaneous and induced abortions according to medical evidence based on prenatal diagnoses of congenital defects), and postnatal anomalies or congenital defects have been recorded up to the first week of life. After the reunification of Germany and the creation of the Federal state of Saxony-Anhalt, the survey of congenital defects included approximately two-thirds of all births with postnatal anomalies and congenital defects in the same federal state. Since 1 January 2000 the survey region includes the entire state of Saxony-Anhalt. Saxony-Anhalt has 2.35 million inhabitants (31.12.2009) and annual births at a rate of 17 144 children (2009). The survey system is multi-centric and based on population.

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. 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).

Sources of ascertainment:
The co-operation partner are (1.1.2010):
- 27 obstetrics departments
- 24 children hospitals
- 10 institutions of prenatal diagnostic
- 6 departments of pathology

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

Background information:
Population based registry (Federal State Saxony-Anhalt); written informed consent of the mother (parents); name and address don't registered; two healthy "controls" per one malformed child; inclusion of terminations of pregnancy, spontaneous abortions after 16th week of gestation, live and stillborn babies; definition of stillbirth: >/= 500 grams; maximum age to include diagnoses: 1 year (almost 1th week of life); annual report (in German).

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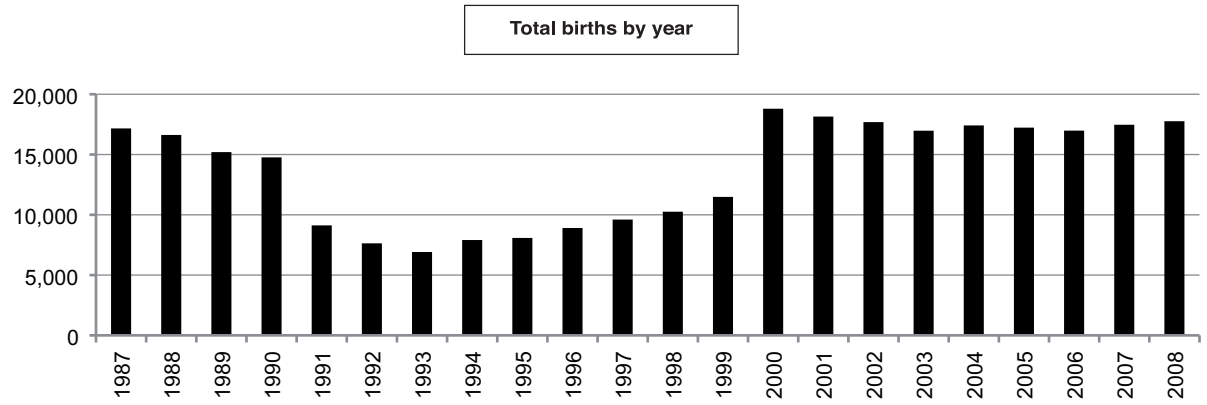
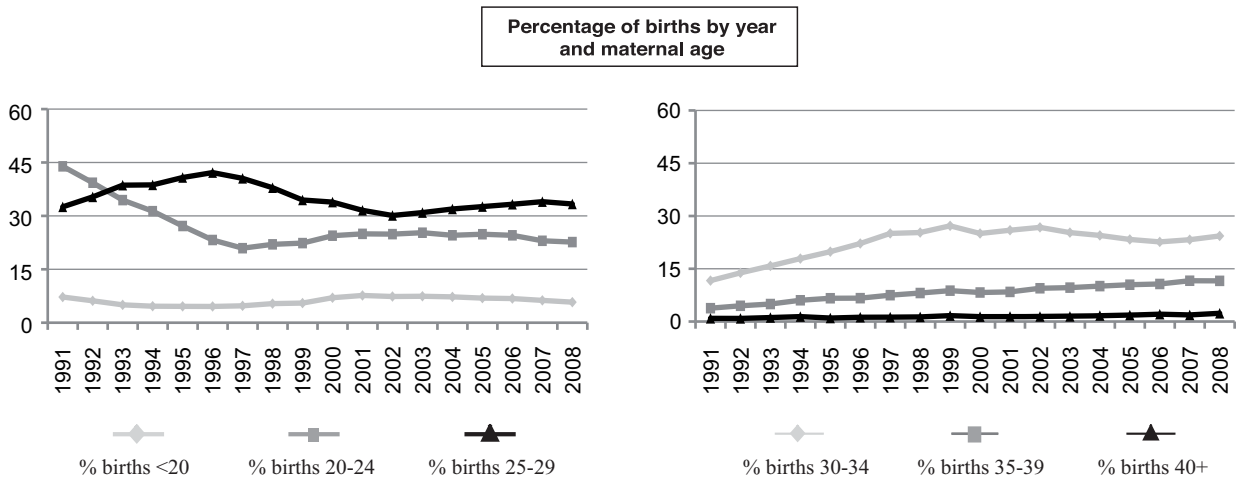
Germany: Saxony Anhalt





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	12	92.3	Cystic kidney	5	12.2
Spina bifida	21	61.8	Limb reduction defects	12	28.6
Encephalocele	4	66.7	Diaphragmatic hernia	1	6.7
Holoprosencephaly	3	60.0	Omphalocele	10	66.7
Hydrocephaly	5	25.0	Gastroschisis	1	4.8
Hypoplastic left heart syndrome	4	23.5	Trisomy 13	6	85.7
Cleft palate without cleft lip	3	6.4	Trisomy 18	16	88.9
Cleft lip with or without cleft palate	9	13.2	Down syndrome	51	54.8
Renal agenesis	6	75.0			

Total ToPs with births defects = 291 (Ratio ToPs/Births: 5.57 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Germany: Saxony Anhalt, 2008

Live births (LB)	17,697
Stillbirths (SB)	66
Total births	17,763
Number of terminations of pregnancy (ToP) for birth defects	99

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	9	5.07
Spina bifida	5	0	11	9.01
Encephalocele	0	0	3	1.69
Microcephaly	19	1	0	11.26
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	4	0	1	2.81
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.56
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	1.13
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	5	0	1	3.38
Tetralogy of Fallot	7	0	0	3.94
Hypoplastic left heart syndrome	7	0	1	4.50
Coarctation of aorta	11	1	0	6.76
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	9	0	1	5.63
Cleft lip with or without cleft palate	15	1	2	10.13
Oesophageal atresia/stenosis with or without fistula	7	0	0	3.94
Small intestine atresia/stenosis	2	0	0	1.13
Anorectal atresia/stenosis	11	0	4	8.44
Undescended testis (36 weeks of gestation or later)	5	0	0	2.81
Hypospadias	13	0	0	7.32
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	1	0	4	2.81
Cystic kidney	7	0	1	4.50
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	9	0	0	5.07
Total Limb reduction defects (include unspecified)	6	3	6	8.44
Transverse	1	1	0	1.13
Preaxial	0	0	0	0.00
Postaxial	0	0	2	1.13
Intercalary	0	0	0	0.00
Mixed	5	2	3	5.63
Unspecified	0	0	1	0.56
Diaphragmatic hernia	7	0	0	3.94
Omphalocele	0	0	3	1.69
Gastroschisis	6	0	0	3.38
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	1	0.56
Trisomy 18	1	1	6	4.50
Down syndrome, all ages (include age unknown)	11	0	23	19.14
<20	0	0	0	0.00
20-24	3	0	2	12.47
25-29	1	0	4	8.47
30-34	4	0	4	18.57
35-39	2	0	7	43.97
40-44	1	0	5	150.38
45+	0	0	1	625.00
unknown	0	0	0	---

Germany: Saxony Anhalt, Previous years rates 1980 - 2008

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

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births		**71,127**	**85,154**	**53,635**	**44,758**	**83,096**	**86,863**
Anencephaly		1.55	3.64	2.24	3.13	2.41	2.53
Spina bifida		4.08	9.04	7.46	6.26	6.14	6.56
Encephalocele		0.28	1.06	1.49	1.79	1.93	1.04
Microcephaly		nr	2.07*	3.17	6.26	10.71	19.23
Holoprosencephaly		nr	2.37*	0.56	1.12	1.08	1.27
Hydrocephaly		nr	5.33*	5.97	10.28	7.94	4.84
Anophthalmos		nr	0.00*	0.75	0.00	0.12	0.23
Microphthalmos		nr	0.89*	1.31	1.56	0.36	0.58
Unspecified Anophthalmos / Microphthalmos		nr	0.00*	0.00	0.00	0.00	0.00
Anotia		nr	0.00*	0.00	0.22	0.12	0.46
Microtia		nr	0.00*	0.19	0.00	1.44	0.46
Unspecified Anotia / Microtia		nr	0.00*	0.00	0.00	0.00	0.00
Transposition of great vessels		nr	3.26*	2.80	5.14	5.66	3.68
Tetralogy of Fallot		nr	1.18*	0.75	2.23	3.13	3.57
Hypoplastic left heart syndrome		nr	3.85*	3.54	4.69	3.73	2.88
Coarctation of aorta		nr	1.78*	1.68	2.90	2.89	4.95
Choanal atresia, bilateral		nr	1.48*	1.12	0.89	0.60	0.23
Cleft palate without cleft lip		nr	4.14*	5.97	7.15	9.87	9.21
Cleft lip with or without cleft palate		nr	13.61*	13.42	16.09	16.25	14.28
Oesophageal atresia / stenosis with or without fistula		nr	2.66*	2.61	2.68	2.65	2.65
Small intestine atresia / stenosis		nr	0.89*	2.61	1.34	2.29	1.84
Anorectal atresia / stenosis		nr	2.96*	3.92	2.23	2.77	5.64
Undescended testis (36 weeks of gestation or later)		nr	10.36*	18.64	12.96	9.87	8.17
Hypospadias		nr	12.73*	17.53	16.76	10.23	8.29
Epispadias		nr	0.30*	0.37	0.67	0.24	0.46
Indeterminate sex		nr	0.89*	0.00	0.45	1.08	0.35
Renal agenesis		nr	2.37*	0.75	2.68	2.29	1.73
Cystic kidney		nr	2.37*	1.68	5.14	4.45	8.63
Bladder exstrophy		nr	0.59*	0.56	0.67	0.00	0.23
Polydactyly, preaxial		nr	0.00*	0.93	4.02	4.21	4.14
Total Limb reduction defects (include unspecified)		nr	3.26*	7.46	6.70	8.18	7.60
Transverse		nr	nr	nr	nr	3.35*	2.19
Preaxial		nr	nr	nr	nr	0.42*	0.46
Postaxial		nr	nr	nr	nr	0.00*	0.58
Intercalary		nr	nr	nr	nr	1.54*	0.81
Mixed		nr	nr	nr	nr	1.68*	3.11
Unspecified		nr	3.26*	7.46	6.70	0.56*	0.46
Diaphragmatic hernia		nr	1.78*	1.49	0.67	2.65	2.65
Omphalocele		nr	5.62*	3.73	2.23	2.89	3.68
Gastroschisis		nr	1.18*	1.86	3.35	2.77	5.07
Unspecified Omphalocele / Gastroschisis		nr	nr	nr	nr	0.14*	0.00
Prune belly sequence		nr	0.00*	0.75	0.89	0.84	0.46
Trisomy 13		0.28	0.35	0.56	2.23	1.08	0.92
Trisomy 18		1.12	0.70	0.75	1.56	2.65	4.03
Down syndrome, all ages (include age unknown)		8.72	7.99	10.44	15.19	16.37	16.35
<20		nr	nr	nr	nr	5.72*	1.75
20-24		nr	nr	nr	nr	6.20*	10.15
25-29		nr	nr	nr	nr	9.74*	7.34
30-34		nr	nr	nr	nr	13.07*	14.67
35-39		nr	nr	nr	nr	55.01*	44.60
40-44		nr	nr	nr	nr	153.06*	146.52
45+		nr	nr	nr	nr	512.82*	294.12
unknown		---	---	---	---	---	---

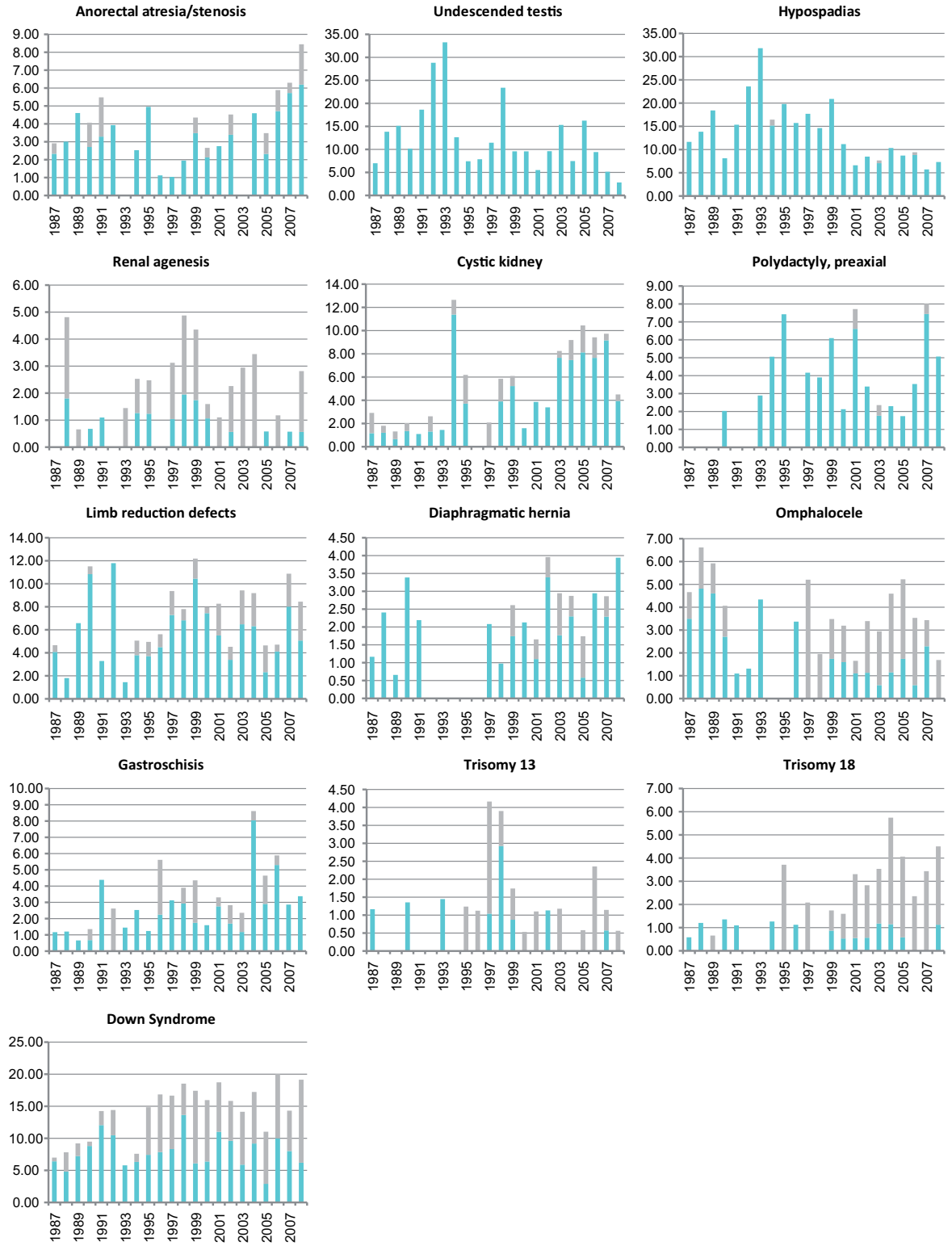
nr = not reported
* data include less than 5 years

Germany: Saxony Anhalt

Time trends 1980-2008 (Birth prevalence rates per 10,000)

Note: L+S rates, ToP rates

Germany: Saxony Anhalt



Note: L+S rates, ToP rates

Hungary
Hungarian Congenital Abnormality Registry

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

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

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

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

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

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

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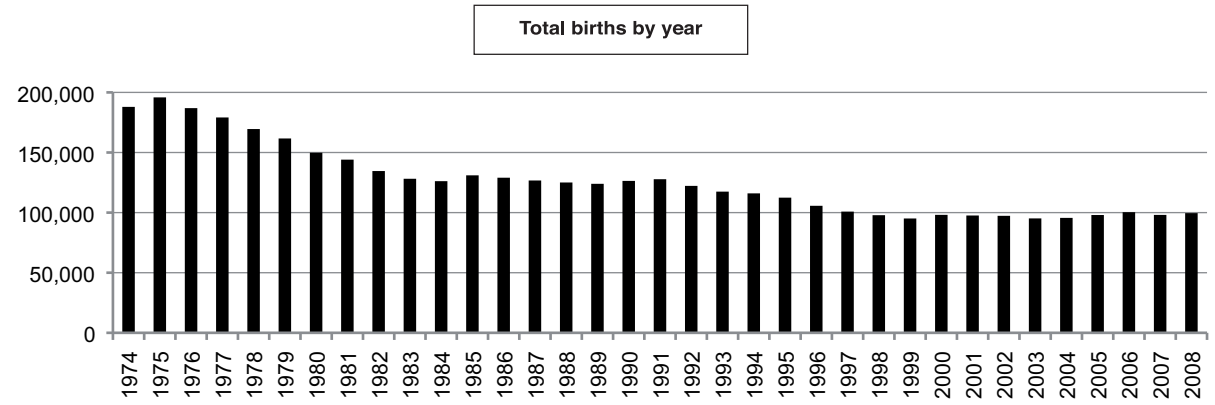
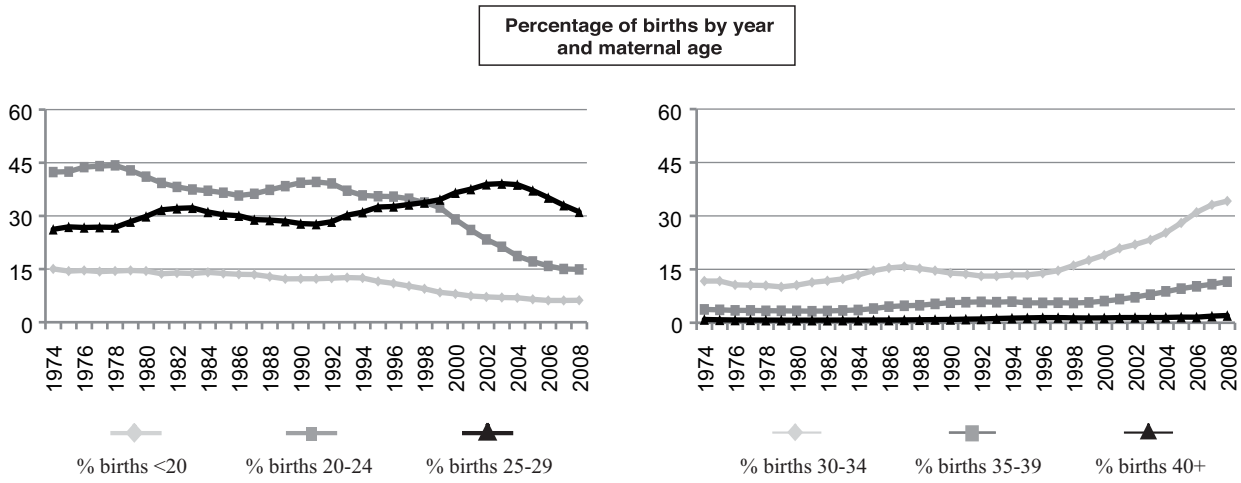
Hungary





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	58	90.6	Cystic kidney	45	30.2
Spina bifida	90	64.3	Limb reduction defects	19	18.3
Encephalocele	11	57.9	Diaphragmatic hernia	14	17.7
Holoprosencephaly	12	75.0	Omphalocele	22	50.0
Hydrocephaly	80	41.9	Gastroschisis	27	65.9
Hypoplastic left heart syndrome	20	23.0	Trisomy 13	29	87.9
Cleft palate without cleft lip	0	0.0	Trisomy 18	63	79.7
Cleft lip with or without cleft palate	13	5.7	Down syndrome	262	51.1
Renal agenesis	20	37.7			

Total ToPs with births defects = 1,247 (Ratio ToPs/Births: 4.18 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Hungary, 2008

Live births (LB)	99,149
Stillbirths (SB)	431
Total births	99,580
Number of terminations of pregnancy (ToP) for birth defects	434

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	0	19	2.21
Spina bifida	19	0	27	4.62
Encephalocele	2	0	5	0.70
Microcephaly	21	0	2	2.31
Holoprosencephaly	4	0	4	0.80
Hydrocephaly	51	0	31	8.23
Anophthalmos	2	0	0	0.20
Microphthalmos	11	0	0	1.10
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	5	0	0	0.50
Microtia	3	0	0	0.30
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	37	0	5	4.22
Tetralogy of Fallot	25	0	1	2.61
Hypoplastic left heart syndrome	22	0	11	3.31
Coarctation of aorta	57	0	0	5.72
Choanal atresia, bilateral	19	0	0	1.91
Cleft palate without cleft lip	67	0	0	6.73
Cleft lip with or without cleft palate	67	0	8	7.53
Oesophageal atresia/stenosis with or without fistula	28	0	0	2.81
Small intestine atresia/stenosis	40	0	2	4.22
Anorectal atresia/stenosis	29	0	2	3.11
Undescended testis (36 weeks of gestation or later)	243	0	0	24.40
Hypospadias	281	0	0	28.22
Epispadias	4	0	0	0.40
Indeterminate sex	5	0	0	0.50
Renal agenesis	23	0	12	3.51
Cystic kidney	45	0	15	6.03
Bladder exstrophy	6	0	0	0.60
Polydactyly, preaxial	3	0	0	0.30
Total Limb reduction defects (include unspecified)	40	0	7	4.72
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	40	0	7	4.72
Diaphragmatic hernia	26	0	4	3.01
Omphalocele	10	0	9	1.91
Gastroschisis	0	0	13	1.31
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	13	1.51
Trisomy 18	8	0	20	2.81
Down syndrome, all ages (include age unknown)	99	3	84	18.68
<20	5	0	0	8.10
20-24	8	2	1	7.41
25-29	15	0	12	8.71
30-34	37	1	20	17.05
35-39	14	0	32	40.01
40-44	4	0	16	102.20
45+	1	0	2	422.54
unknown	15	0	1	---

nr = not reported
Unilateral Choanal atresia included

Hungary, Previous years rates 1974 - 2008

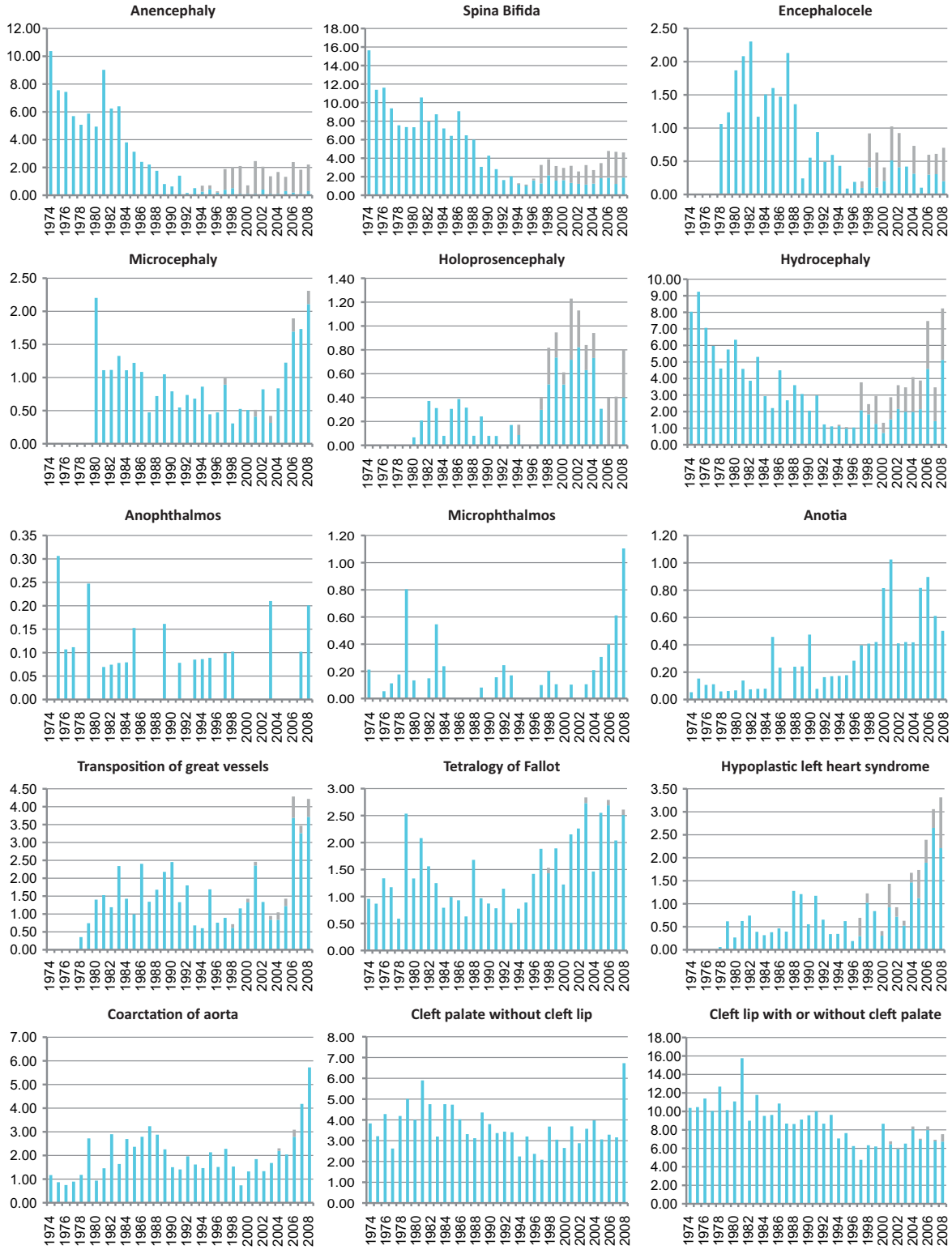
Isolated cases only
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**919,396**	**718,307**	**637,980**	**617,808**	**532,809**	**483,352**	**491,653**
Anencephaly	7.29	6.47	2.66	0.71	1.09	1.74	1.89
Spina bifida	11.20	8.35	7.04	2.78	2.21	3.02	4.07
Encephalocele	1.06*	1.73	1.61	0.57	0.36	0.68	0.55
Microcephaly	nr	1.46*	0.92	0.76	0.62	0.56	1.61
Holoprosencephaly	nr	0.23*	0.24	0.11	0.26	0.95	0.57
Hydrocephaly	7.06	5.21	3.18	2.10	1.86	2.83	5.45
Anophthalmos	0.11	0.10	0.05	0.06	0.08	0.04	0.06
Microphthalmos	0.11	0.33	0.05	0.13	0.06	0.06	0.53
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.10	0.08	0.20	0.23	0.28	0.62	0.65
Microtia	0.05	0.03	0.02	0.02	0.02	0.10	0.14
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	0.35*	1.41	1.57	1.70	0.94	1.47	2.91
Tetralogy of Fallot	0.99	1.78	1.00	0.86	1.28	2.07	2.30
Hypoplastic left heart syndrome	0.06*	0.53	0.56	0.79	0.60	0.85	2.44
Coarctation of aorta	0.97	1.94	2.79	1.75	1.78	1.39	3.48
Choanal atresia, bilateral	nr	0.13*	0.16	0.16	0.06	0.06	0.53
Cleft palate without cleft lip	3.62	4.61	4.00	3.67	2.70	3.17	4.05
Cleft lip with or without cleft palate	10.96	11.54	9.47	9.40	6.46	6.85	7.65
Oesophageal atresia / stenosis with or without fistula	2.09*	1.80	1.63	1.60	0.98	0.99	1.69
Small intestine atresia / stenosis	nr	1.46*	1.29	1.13	0.60	0.77	1.89
Anorectal atresia / stenosis	2.42	2.14	2.13	1.62	0.90	0.93	1.99
Undescended testis (36 weeks of gestation or later)	nr	16.91	17.54	14.99	12.57	10.51	20.12
Hypospadias	17.56	16.86	21.40	21.50	19.13	21.85	26.83
Epispadias	nr	nr	nr	nr	nr	nr	0.40*
Indeterminate sex	nr	0.22*	0.36	0.31	0.13	0.29	0.45
Renal agenesis	1.06*	1.28	0.89	1.05	0.13	0.21	1.42
Cystic kidney	nr	0.00*	0.11	0.52	1.03	2.01	4.50
Bladder exstrophy	nr	0.34*	0.49	0.08	0.04	0.10	0.26
Polydactyly, preaxial	nr	0.90*	1.82	1.46	3.62	7.94	6.85
Total Limb reduction defects (include unspecified)	nr	4.34*	4.26	3.08	2.95	2.88	3.60
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	4.34*	4.26	3.08	2.95	2.88	3.60
Diaphragmatic hernia	2.08	2.17	2.07	1.99	0.94	0.35	1.93
Omphalocele	nr	2.44*	1.43	0.83	0.79	0.99	1.32
Gastroschisis	nr	0.65*	0.50	0.55	0.49	0.83	1.04
Unspecified Omphalocele / Gastroschisis	nr	0.00*	0.00	0.00	0.00	0.00	0.00
Prune belly sequence	nr	nr	nr	nr	0.09	0.00	0.06
Trisomy 13	nr	0.11*	0.25	0.19	0.24	0.43	1.10
Trisomy 18	nr	0.23*	0.25	0.34	0.43	1.22	2.40
Down syndrome, all ages (include age unknown)	9.00	8.59	7.70	8.82	6.53	13.26	16.01
<20	nr	1.65*	1.39	2.23	1.54	5.45	8.95
20-24	nr	1.11*	2.83	2.67	2.19	6.74	6.98
25-29	nr	3.43*	4.04	3.58	2.13	8.48	7.55
30-34	nr	5.37*	4.95	4.84	4.61	11.99	14.40
35-39	nr	6.77*	14.41	24.29	11.27	37.10	43.64
40-44	nr	67.81*	50.52	98.32	61.03	165.98	136.49
45+	nr	nr	nr	nr	nr	nr	422.54*
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

Hungary

Time trends 1974-2008 (Birth prevalence rates per 10,000)

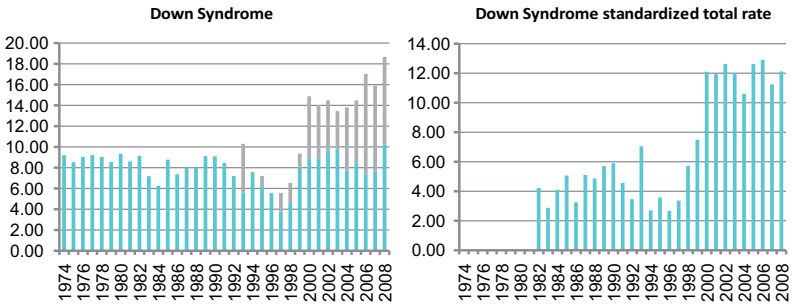


Note: L+S rates, ToP rates

Hungary

Note: L+S rates, ToP rates

Hungary


Down Syndrome
20.00
18.00
16.00
14.00
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1974 1976 1978 1980 1982 1984 1986 1988 1990 1992 1994 1996 1998 2000 2002 2004 2006 2008
Down Syndrome standardized total rate
14.00
12.00
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6.00
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1974 1976 1978 1980 1982 1984 1986 1988 1990 1992 1994 1996 1998 2000 2002 2004 2006 2008

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

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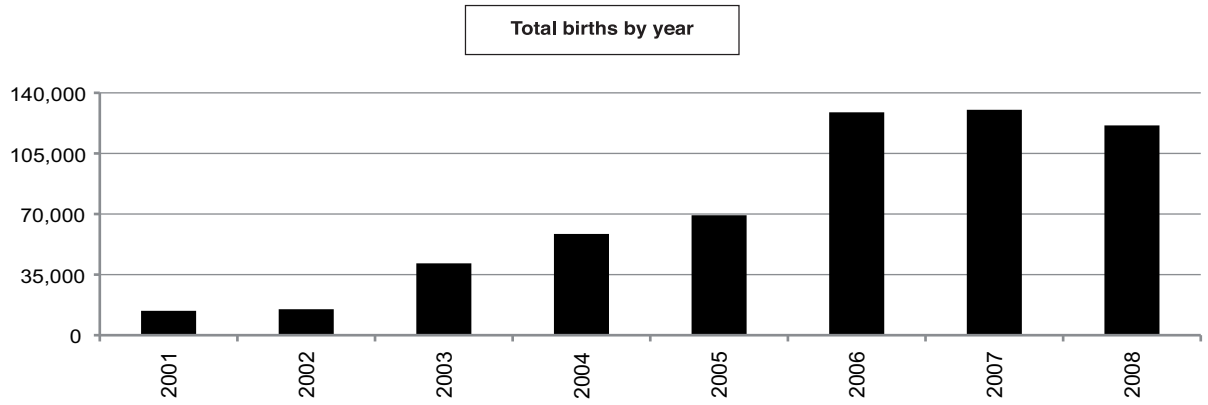
India: BDRI



Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	275	57.1	Cystic kidney	54	47.4
Spina bifida	176	39.5	Limb reduction defects	43	19.8
Encephalocele	59	54.1	Diaphragmatic hernia	26	26.5
Holoprosencephaly	31	73.8	Omphalocele	38	41.8
Hydrocephaly	106	30.5	Gastroschisis	9	40.9
Hypoplastic left heart syndrome	18	40.9	Trisomy 13	0	0.0
Cleft palate without cleft lip	11	17.2	Trisomy 18	13	86.7
Cleft lip with or without cleft palate	33	15.1	Down syndrome	9	26.5
Renal agenesis	42	61.8			

Total ToPs with births defects = 1063 (Ratio ToPs/Births: 2.80 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

India: BDRI, 2008

Live births (LB)	118,607
Stillbirths (SB)	2,579
Total births	121,186
Number of terminations of pregnancy (ToP) for birth defects	317

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	13	70	80	13.45
Spina bifida	71	50	67	15.51
Encephalocele	6	7	11	1.98
Microcephaly	10	3	7	1.65
Holoprosencephaly	1	2	7	0.83
Hydrocephaly	54	52	37	11.80
Anophthalmos	0	0	0	0.00
Microphthalmos	3	1	0	0.33
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.08
Microtia	1	0	0	0.08
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	3	1	2	0.50
Tetralogy of Fallot	2	4	3	0.74
Hypoplastic left heart syndrome	6	1	8	1.24
Coarctation of aorta	2	0	0	0.17
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	15	2	1	1.49
Cleft lip with or without cleft palate	57	16	7	6.60
Oesophageal atresia/stenosis with or without fistula	19	1	1	1.73
Small intestine atresia/stenosis	4	2	1	0.58
Anorectal atresia/stenosis	21	3	8	2.64
Undescended testis (36 weeks of gestation or later)	12	0	0	0.99
Hypospadias	22	1	0	1.90
Epispadias	0	0	0	0.00
Indeterminate sex	1	8	3	0.99
Renal agenesis	5	3	10	1.49
Cystic kidney	19	8	15	3.47
Bladder exstrophy	1	1	5	0.58
Polydactyly, preaxial	35	8	4	3.88
Total Limb reduction defects (include unspecified)	24	12	3	3.22
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	22	6	10	3.14
Omphalocele	8	16	12	2.97
Gastroschisis	4	2	3	0.74
Unspecified Omphalocele/Gastroschisis	0	0	3	0.25
Prune belly sequence	3	3	2	0.66
Trisomy 13	0	0	0	0.00
Trisomy 18	1	0	2	0.25
Down syndrome, all ages (include age unknown)	9	1	5	1.24
<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+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported

India: BDRI, Previous years rates 2001 - 2008

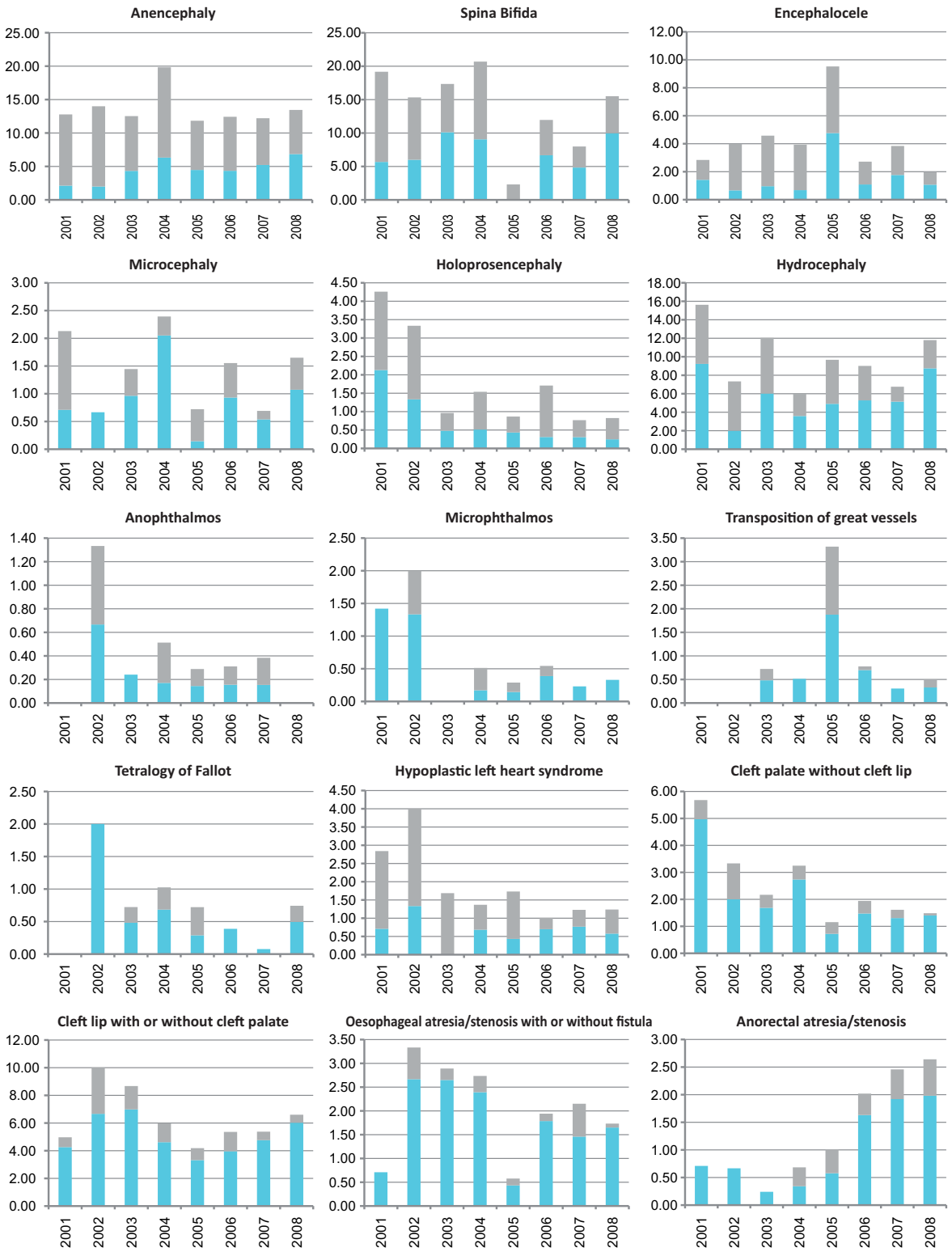
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003*	2004-2008
Total births							
Anencephaly						12.89	13.39
Spina bifida						17.28	11.48
Encephalocele						4.11	3.90
Microcephaly						1.42	1.34
Holoprosencephaly						2.12	1.12
Hydrocephaly						11.76	8.84
Anophthalmos						0.42	0.28
Microphthalmos						0.71	0.37
Unspecified Anophthalmos / Microphthalmos						0.00	0.02
Anotia						0.00	0.04
Microtia						0.14	0.02
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						0.42	0.91
Tetralogy of Fallot						0.85	0.51
Hypoplastic left heart syndrome						2.41	1.26
Coarctation of aorta						0.99	0.26
Choanal atresia, bilateral						0.14	0.10
Cleft palate without cleft lip						3.12	1.79
Cleft lip with or without cleft palate						8.22	5.57
Oesophageal atresia / stenosis with or without fistula						2.55	1.85
Small intestine atresia / stenosis						0.71	0.65
Anorectal atresia / stenosis						0.42	1.99
Undescended testis (36 weeks of gestation or later)						1.13	1.06
Hypospadias						2.69	1.85
Epispadias						0.00	0.00
Indeterminate sex						3.26	1.65
Renal agenesis						3.82	1.99
Cystic kidney						5.81	3.33
Bladder exstrophy						0.99	0.55
Polydactyly, preaxial						3.40	3.33
Total Limb reduction defects (include unspecified)						8.07	6.22
Transverse						nr	0.00*
Preaxial						nr	0.00*
Postaxial						nr	0.00*
Intercalary						nr	0.00*
Mixed						nr	0.00*
Unspecified						nr	0.00*
Diaphragmatic hernia						4.25	2.72
Omphalocele						4.39	2.36
Gastroschisis						0.71	0.63
Unspecified Omphalocele / Gastroschisis						0.00	0.14
Prune belly sequence						0.42	0.18
Trisomy 13						0.14	0.08
Trisomy 18						0.42	0.43
Down syndrome, all ages (include age unknown)						0.99	1.04
<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 2001-2008 (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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Iran:TRoCA, 2008

Live births (LB)	21,476
Stillbirths (SB)	211
Total births	21,687
Number of terminations of pregnancy (ToP) for birth defects	15

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	nr	3	7	4.61
Spina bifida	3	nr	1	1.84
Encephalocele	2	nr	nr	0.92
Microcephaly	11	nr	nr	5.07
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	18	7	4	13.37
Anophthalmos	nr	nr	nr	nr
Microphthalmos	nr	nr	nr	nr
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	nr	nr	nr	nr
Microtia	1	nr	nr	nr
Unspecified Anotia/Microtia	2	2	nr	1.84
Transposition of great vessels	18	nr	nr	8.30
Tetralogy of Fallot	1	nr	nr	0.46
Hypoplastic left heart syndrome	7	nr	nr	3.23
Coarctation of aorta	nr	nr	nr	nr
Choanal atresia, bilateral	nr	nr	nr	nr
Cleft palate without cleft lip	13	nr	nr	5.99
Cleft lip with or without cleft palate	19	nr	nr	8.76
Oesophageal atresia/stenosis with or without fistula	32	nr	nr	14.76
Small intestine atresia/stenosis	25	nr	nr	11.53
Anorectal atresia/stenosis	9	nr	nr	4.15
Undescended testis (36 weeks of gestation or later)	19	nr	nr	8.76
Hypospadias	21	nr	nr	9.68
Epispadias	2	nr	nr	0.92
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	3	nr	nr	1.38
Cystic kidney	1	nr	nr	0.46
Bladder exstrophy	nr	nr	nr	nr
Polydactyly, preaxial	8	nr	nr	3.69
Total Limb reduction defects (include unspecified)	44	3	nr	21.67
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	44	3	nr	21.67
Diaphragmatic hernia	13	nr	nr	5.99
Omphalocele	nr	nr	nr	nr
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	2	nr	nr	0.92
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	3	nr	nr	1.38
Trisomy 18	1	nr	nr	0.46
Down syndrome, all ages (include age unknown)	24	1	2	12.45
<20	1	nr	nr	2.72
20-24	2	nr	nr	3.05
25-29	9	nr	nr	15.13
30-34	3	nr	1	11.16
35-39	6	nr	1	47.91
40-44	2	1	nr	80.86
45+	1	nr	nr	144.93
unknown	0	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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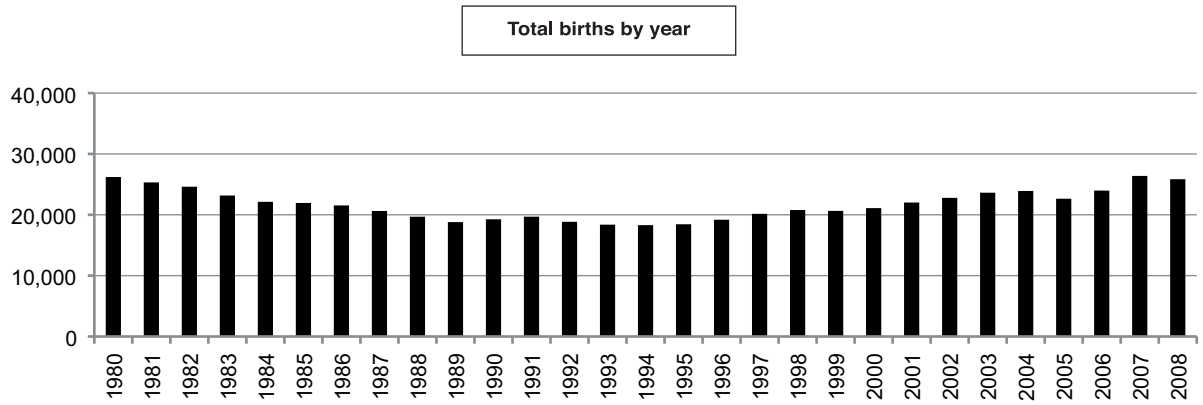
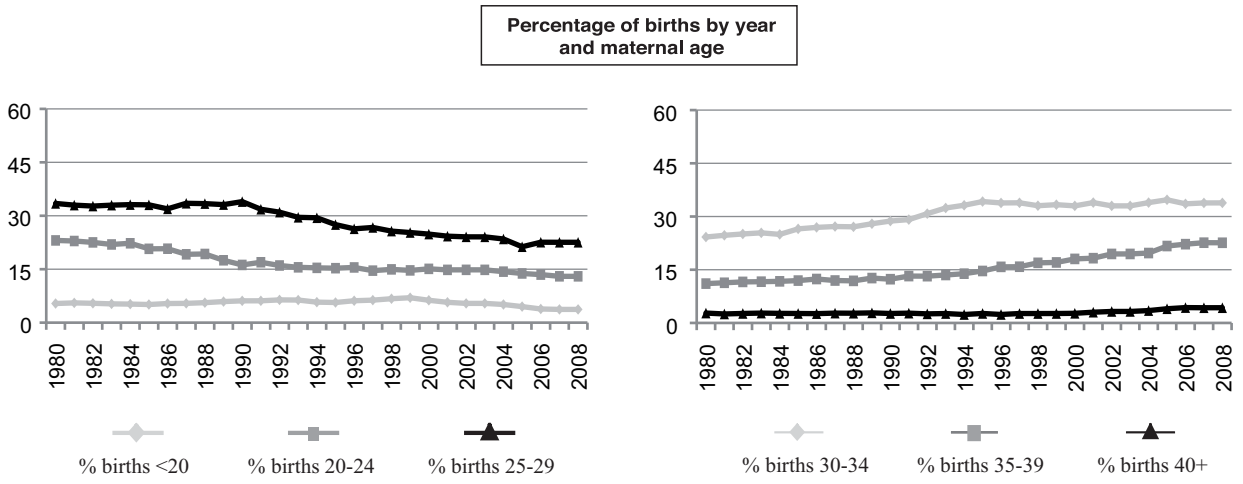




Ireland: Dublin, 2008

Live births (LB)	25,724
Stillbirths (SB)	120
Total births	25,844
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	4		3.10
Spina bifida	6	0		2.32
Encephalocele	1	2		1.16
Microcephaly	7	1		3.10
Holoprosencephaly	1	1		0.77
Hydrocephaly	4	2		2.32
Anophthalmos	0	0		0.00
Microphthalmos	3	0		1.16
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	2	0		0.77
Microtia	0	0		0.00
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	8	0		3.10
Tetralogy of Fallot	6	0		2.32
Hypoplastic left heart syndrome	3	0		1.16
Coarctation of aorta	11	0		4.26
Choanal atresia, bilateral	5	0		1.93
Cleft palate without cleft lip	13	1		5.42
Cleft lip with or without cleft palate	17	1		6.96
Oesophageal atresia/stenosis with or without fistula	3	1		1.55
Small intestine atresia/stenosis	1	0		0.39
Anorectal atresia/stenosis	10	1		4.26
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	27	0		10.45
Epispadias	nr	nr		nr
Indeterminate sex	2	0		0.77
Renal agenesis	3	4		2.71
Cystic kidney	7	1		3.10
Bladder exstrophy	0	1		0.39
Polydactyly, preaxial	19	0		7.35
Total Limb reduction defects (include unspecified)	8	1		3.48
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	8	1		3.48
Diaphragmatic hernia	13	0		5.03
Omphalocele	3	1		1.55
Gastroschisis	5	0		1.93
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	3	0		1.16
Trisomy 18	6	5		4.26
Down syndrome, all ages (include age unknown)	63	3		25.54
<20	0	0		0.00*
20-24	4	0		11.96*
25-29	11	0		18.96*
30-34	17	1		20.68*
35-39	20	2		37.85*
40-44	11	0		104.07*
45+	0	0		0.00
unknown	0	0		---

nr = not reported
* Estimated

Ireland: Dublin, Previous years rates 1980 - 2008

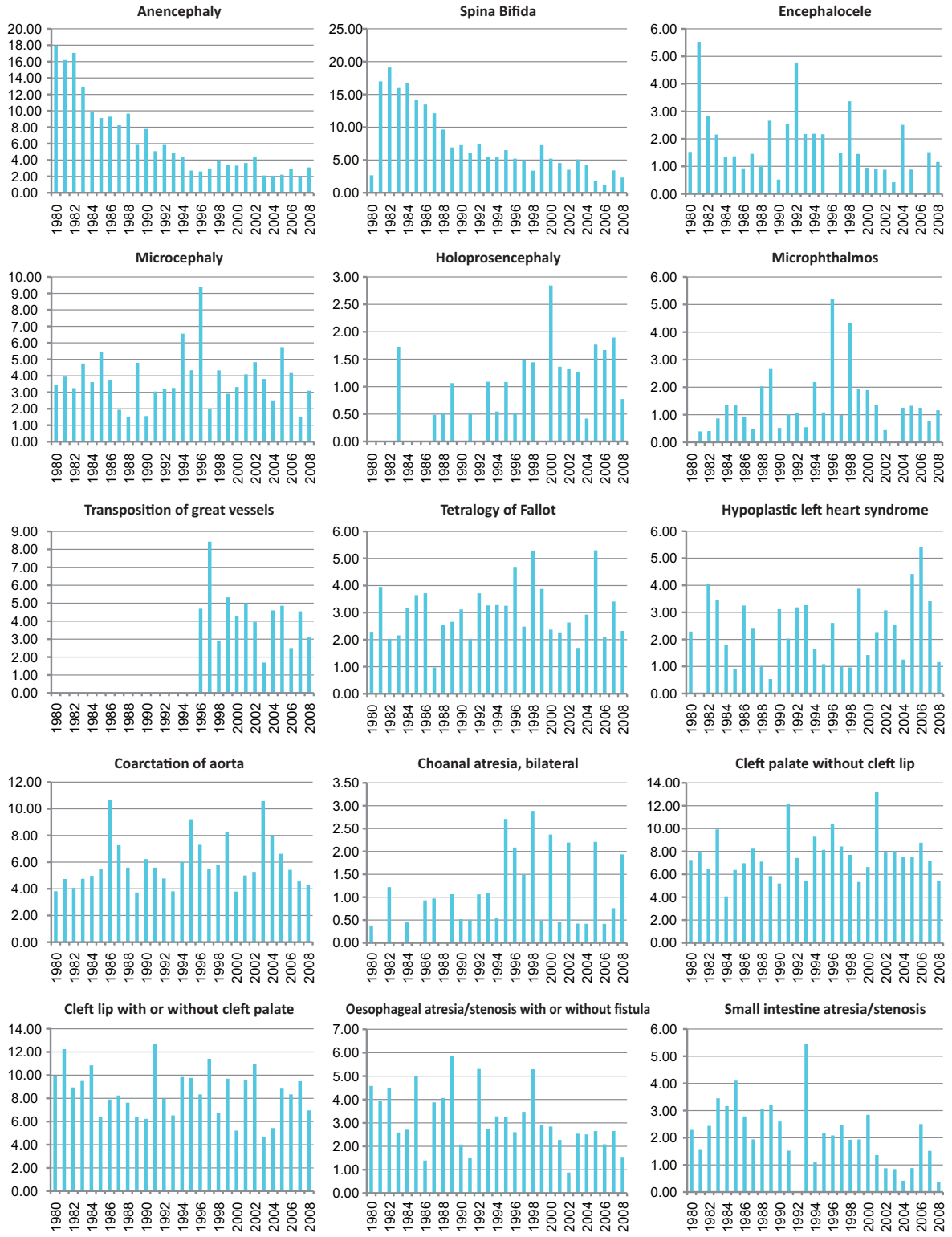
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**99,297**	**105,916**	**94,974**	**96,865**	**110,162**	**122,761**	
Anencephaly	16.11	9.25	5.90	3.30	3.36	2.44	
Spina bifida	13.49	13.31	6.63	5.06	5.08	2.61	
Encephalocele	3.02	1.23	2.53	1.86	0.91	1.22	
Microcephaly	3.83	3.30	3.16	5.27	3.81	3.58	
Holoprosencephaly	0.40	0.19	0.53	1.03	1.36	1.38	
Hydrocephaly	nr	nr	nr	2.49*	2.09	2.20	
Anophthalmos	0.30	0.09	0.21	0.83	0.18	0.24	
Microphthalmos	0.40	1.23	1.16	2.79	1.09	1.14	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.18	0.00	
Anotia	nr	nr	nr	nr	0.22*	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*	3.99	3.91	
Tetralogy of Fallot	2.62	2.83	2.95	3.82	2.54	3.18	
Hypoplastic left heart syndrome	2.42	1.89	2.42	1.45	2.63	3.10	
Coarctation of aorta	4.33	6.80	4.84	6.71	6.63	5.70	
Choanal atresia, bilateral	0.40	0.47	0.84	1.96	1.18	1.14	
Cleft palate without cleft lip	7.86	6.51	7.27	8.78	8.26	7.25	
Cleft lip with or without cleft palate	10.17	8.21	8.00	9.19	7.99	7.90	
Oesophageal atresia / stenosis with or without fistula	3.93	3.40	3.47	3.61	2.27	2.28	
Small intestine atresia / stenosis	2.42	3.02	2.53	1.96	1.54	1.14	
Anorectal atresia / stenosis	3.42	3.78	3.05	2.68	2.27	3.58	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	
Hypospadias	14.20	11.90	12.85	16.31	16.16	11.16	
Epispadias	nr	nr	nr	nr	nr	nr	
Indeterminate sex	0.20	0.09	0.21	0.52	0.18	0.33	
Renal agenesis	4.63	4.91	4.74	3.82	2.63	2.04	
Cystic kidney	2.82	3.12	2.53	5.16	2.63	4.64	
Bladder exstrophy	nr	nr	nr	0.83*	0.64	0.81	
Polydactyly, preaxial	5.64	6.89	5.90	5.68	10.35	7.74	
Total Limb reduction defects (include unspecified)	4.33	3.21	4.42	4.65	4.54	3.58	
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	4.33	3.21	4.42	4.65	4.54	3.58	
Diaphragmatic hernia	3.12	3.40	5.16	4.34	4.08	3.50	
Omphalocele	2.42	2.45	1.79	2.89	3.72	2.61	
Gastroschisis	0.20	0.57	0.74	1.55	2.90	3.10	
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.00	
Prune belly sequence	0.10	0.28	0.32	0.72	0.36	0.65	
Trisomy 13	1.21	0.76	1.05	2.17	3.00	1.96	
Trisomy 18	2.42	1.70	2.95	3.61	4.36	4.15	
Down syndrome, all ages (include age unknown)	18.23	19.45	19.48	22.51	20.79	24.68	
<20	nr	nr	21.17*	10.11	4.60	11.84	
20-24	nr	nr	11.95*	8.20	5.52	9.71	
25-29	nr	nr	9.78*	9.92	7.06	10.19	
30-34	nr	nr	13.64*	19.37	15.87	18.57	
35-39	nr	nr	40.37	46.77	47.24	46.61	
40-44	nr	nr	215.52*	151.58	128.69	106.34	
45+	nr	nr	1282.05*	531.91	306.12	52.36	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

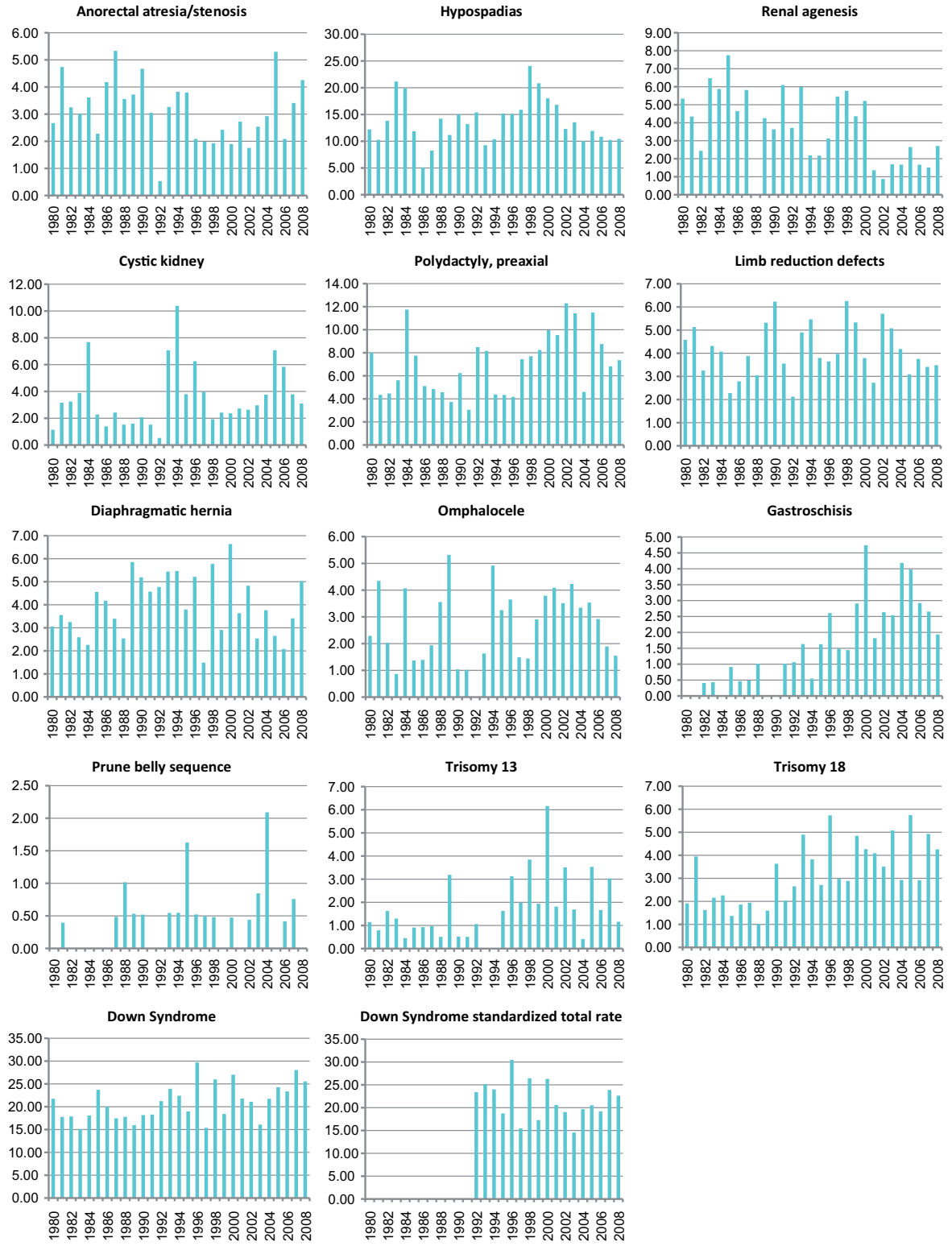
Ireland: Dublin

Time trends 1980-2008 (Birth prevalence rates per 10,000)



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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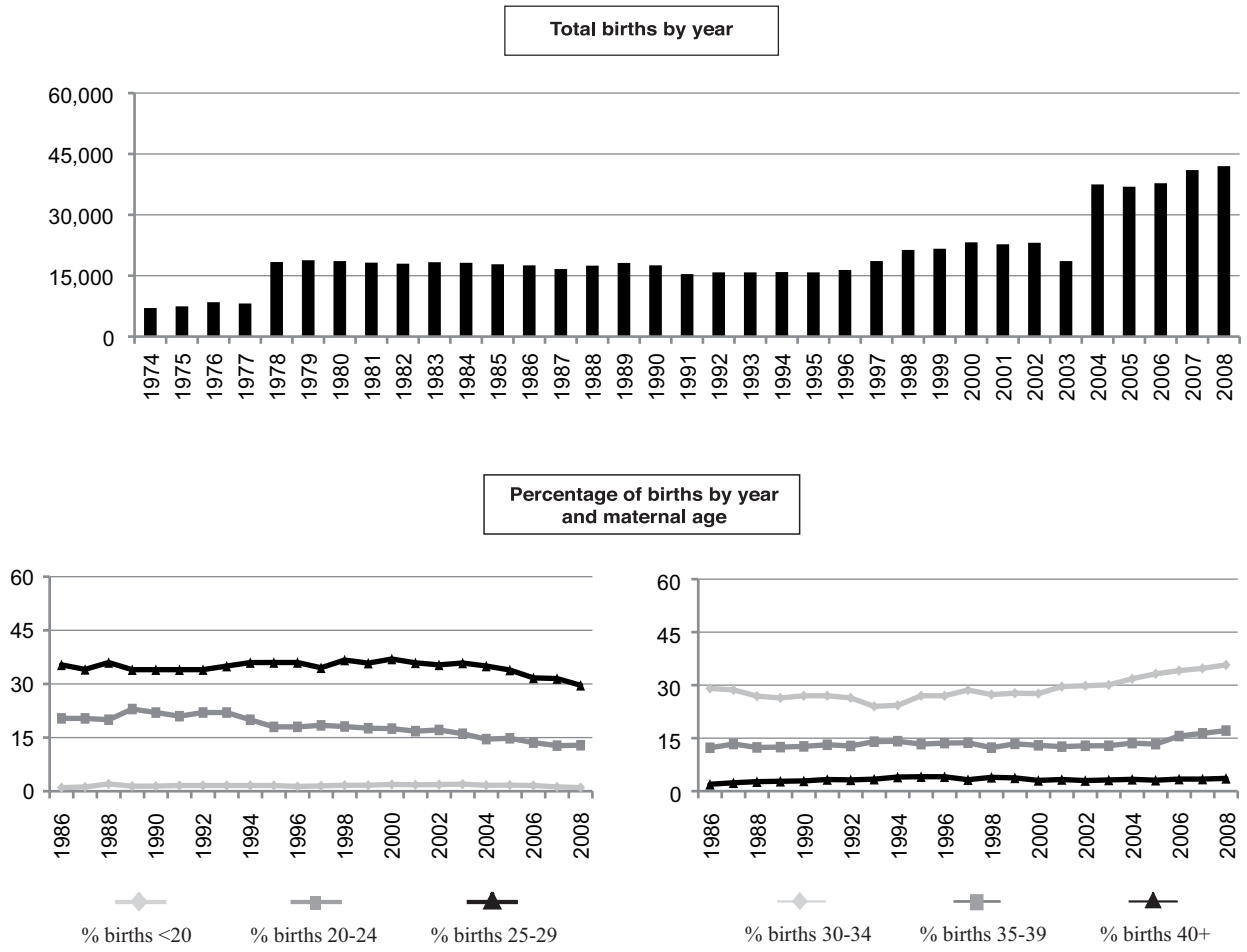
Israel: IBDSP



Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	2	16.7	Cystic kidney	0	0.0
Spina bifida	8	25.8	Limb reduction defects	1	5.9
Encephalocele	1	12.5	Diaphragmatic hernia	0	0.0
Holoprosencephaly	2	50.0	Omphalocele	0	0.0
Hydrocephaly	12	26.1	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	1	4.3	Trisomy 13	0	0.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	1	20.0
Cleft lip with or without cleft palate	6	12.2	Down syndrome	12	13.2
Renal agenesis	1	10.0			

Total ToPs with births defects = 63 (Ratio ToPs/Births: 0.52 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Israel: IBDSP, 2008

Live births (LB)	41,675
Stillbirths (SB)	323
Total births	41,998
Number of terminations of pregnancy (ToP) for birth defects	32

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	2	1	0.95
Spina bifida	11	2	4	4.05
Encephalocele	3	0	1	0.95
Microcephaly	8	0	3	2.62
Holoprosencephaly	0	0	2	0.48
Hydrocephaly	12	0	2	3.33
Anophthalmos	0	0	1	0.24
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	4	0	0	0.95
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	11	1	3	3.57
Tetralogy of Fallot	12	0	3	3.57
Hypoplastic left heart syndrome	8	0	1	2.14
Coarctation of aorta	17	0	0	4.05
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	21	0	0	5.00
Cleft lip with or without cleft palate	15	0	3	4.29
Oesophageal atresia/stenosis with or without fistula	15	0	0	3.57
Small intestine atresia/stenosis	3	0	0	0.71
Anorectal atresia/stenosis	8	0	0	1.90
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	172	0	0	40.95
Epispadias	2	0	0	0.48
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	0	0	0	0.00
Cystic kidney	4	0	0	0.95
Bladder exstrophy	3	0	0	0.71
Polydactyly, preaxial	7	0	0	1.67
Total Limb reduction defects (include unspecified)	1	0	0	0.24
Transverse	0	0	0	0.00
Preaxial	1	0	0	0.24
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	0	0	0	0.00
Diaphragmatic hernia	7	0	0	1.67
Omphalocele	0	0	0	0.00
Gastroschisis	0	0	0	0.00
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.24
Trisomy 13	1	0	0	0.24
Trisomy 18	1	0	1	0.48
Down syndrome, all ages (include age unknown)	34	0	6	9.52
<20	0	0	0	0.00
20-24	3	0	0	5.55
25-29	6	0	0	4.82
30-34	9	0	0	6.00
35-39	8	0	2	13.89
40-44	6	0	4	74.63
45+	2	0	0	111.11
unknown	0	0	0	---

nr = not reported

Israel: IBDSP, Previous years rates 1974 - 2008

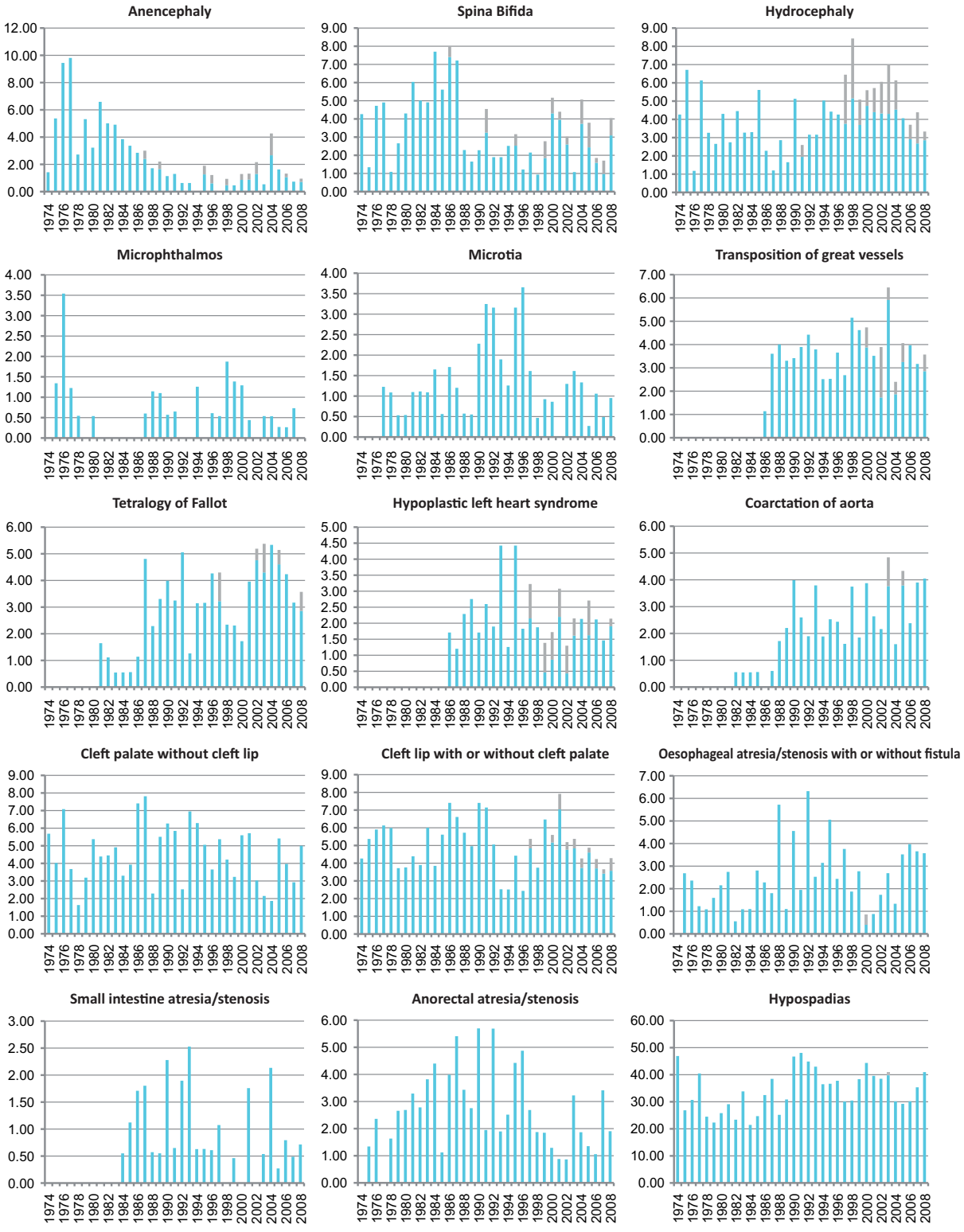
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**49,485**	**91,919**	**87,670**	**82,748**	**88,101**	**109,335**	**195,225**
Anencephaly	5.25	5.00	2.97	1.21	0.79	1.19	1.74
Spina bifida	2.83	4.57	6.16	2.42	1.93	3.38	3.28
Encephalocele	0.40	0.33	0.34	1.21	0.34	0.27	0.56
Microcephaly	nr	nr	0.00*	0.00	0.00	2.84	1.84
Holoprosencephaly	nr	nr	0.23	0.48	0.00	0.00	0.41
Hydrocephaly	4.04	3.48	3.08	3.14	5.90	5.85	4.30
Anophthalmos	0.00	0.00	0.00	0.00	0.00	0.18	0.05
Microphthalmos	1.21	0.11	0.34	0.48	0.91	0.73	0.36
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.00	0.00	0.00	0.00	0.11	0.00	0.00
Microtia	0.61	0.87	1.14	2.18	1.93	0.91	0.82
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	nr	2.90*	3.75	3.41	4.57	3.43
Tetralogy of Fallot	nr	0.82	1.83	3.38	3.41	3.66	4.25
Hypoplastic left heart syndrome	nr	nr	1.74*	2.66	2.50	1.92	2.10
Coarctation of aorta	nr	0.27	0.68	2.90	2.50	3.02	3.28
Choanal atresia, bilateral	nr	nr	0.34	0.24	0.11	0.18	0.05
Cleft palate without cleft lip	3.84	4.46	4.90	5.44	4.88	4.02	3.84
Cleft lip with or without cleft palate	5.66	4.35	5.82	5.44	3.75	6.13	4.25
Oesophageal atresia / stenosis with or without fistula	1.41	1.63	2.74	3.26	3.18	1.74	3.23
Small intestine atresia / stenosis	nr	nr	1.14	1.57	0.57	0.55	0.87
Anorectal atresia / stenosis	1.21	3.05	3.65	3.63	3.18	1.55	1.95
Undescended testis (36 weeks of gestation or later)	nr	nr	0.00*	0.00	0.00	nr	0.00*
Hypospadias	31.73	26.87	28.29	42.42	33.94	40.33	33.40
Epispadias	0.20	0.00	0.11	0.24	0.00	0.46	0.10
Indeterminate sex	nr	nr	0.00*	0.00	0.00	0.00*	0.17*
Renal agenesis	nr	nr	0.97*	0.73	0.57	0.37	1.08
Cystic kidney	0.81	0.54	1.14	1.21	1.14	2.47	1.28
Bladder exstrophy	0.20	0.22	0.57	0.48	0.23	0.27	0.46
Polydactyly, preaxial	0.20	0.65	0.34	0.36	1.14	1.01	0.87
Total Limb reduction defects (include unspecified)	3.84	2.61	3.08	3.14	2.04	1.37	2.00
Transverse	nr	0.28*	1.03	1.81	0.68	0.55	1.02
Preaxial	nr	0.55*	0.80	0.12	0.79	0.46	0.56
Postaxial	nr	0.83*	0.11	0.36	0.34	0.09	0.05
Intercalary	nr	0.00*	0.57	0.24	0.00	0.18	0.26
Mixed	nr	0.55	0.57	0.60	0.23	0.09	0.10
Unspecified	3.84	0.00*	0.00	0.00	0.00	0.00	0.00
Diaphragmatic hernia	2.18*	2.39	2.05	3.02	1.59	1.65	1.84
Omphalocele	1.82	2.28	1.37	1.09	0.45	0.91	0.77
Gastroschisis	0.00*	0.22	0.80	0.00	0.11	0.46	0.20
Unspecified Omphalocele / Gastroschisis	0.00*	0.00	0.00	0.00	0.11	0.09	0.00
Prune belly sequence	0.40	0.33	0.00	0.12	0.11	0.09	0.20
Trisomy 13	nr	nr	0.34	0.60	0.45	0.37	0.36
Trisomy 18	nr	nr	0.57	0.60	0.91	1.74	0.61
Down syndrome, all ages (include age unknown)	11.72	9.25	12.78	8.58	7.04	10.52	8.55
<20	nr	nr	nr	0.00*	0.00	4.99	10.80
20-24	nr	nr	nr	0.00*	1.84	2.69	4.87
25-29	nr	nr	nr	2.48*	4.12	6.36	3.49
30-34	nr	nr	nr	7.42*	5.90	8.23	5.28
35-39	nr	nr	nr	19.16*	12.75	21.97	15.43
40-44	nr	nr	nr	41.67*	46.24	70.79	72.83
45+	nr	nr	nr	90.91*	82.64	133.33	70.32
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

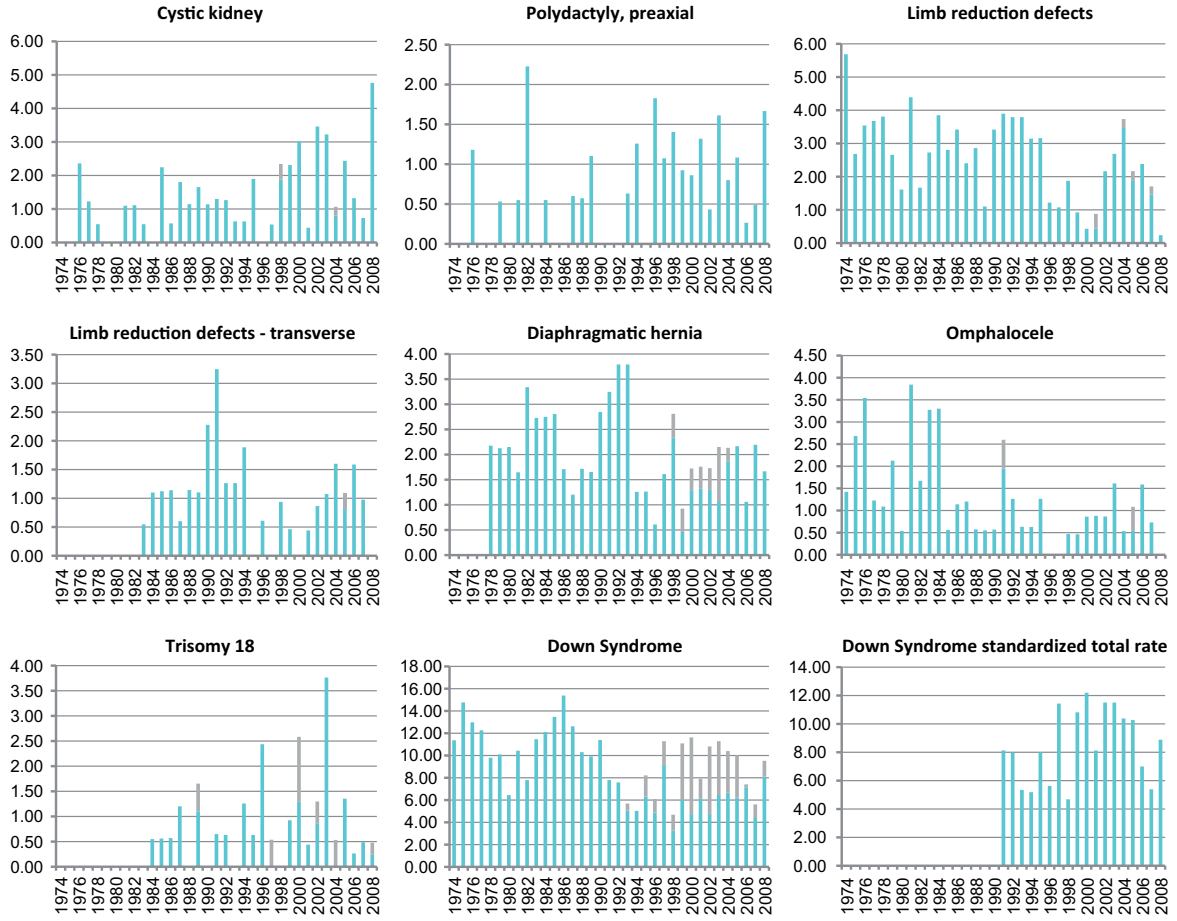
Israel: IBDSP

Time trends 1974-2008 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

Israel: IBDSP



Note: L+S rates, ToP rates

Italy - Campania: BDRCam
Birth Defects Registry of Campania

History:
The Registry started in 1991and 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.

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 specialties 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.

Addresses and Staff:
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82100 Benevento, Italy
Phone: 39- 0824-57374
Fax: 39-0824-57495
E-mail: giorecam@tin.it

Italy: BDRCam, 2008

Live births (LB)	61,615
Stillbirths (SB)	114
Total births	61,729
Number of terminations of pregnancy (ToP) for birth defects	313

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	19	3.40
Spina bifida	5	0	13	2.92
Encephalocele	1	0	3	0.65
Microcephaly	17	0	0	2.75
Holoprosencephaly	14	0	11	4.05
Hydrocephaly	32	0	24	9.07
Anophthalmos	0	0	0	0.00
Microphthalmos	4	0	0	0.65
Unspecified Anophthalmos/Microphthalmos	2	0	0	0.32
Anotia	5	0	0	0.81
Microtia	2	0	0	0.32
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	37	0	0	5.99
Tetralogy of Fallot	21	0	4	4.05
Hypoplastic left heart syndrome	4	0	16	3.24
Coarctation of aorta	24	0	0	3.89
Choanal atresia, bilateral	9	0	2	1.78
Cleft palate without cleft lip	36	0	2	6.16
Cleft lip with or without cleft palate	32	0	4	5.83
Oesophageal atresia/stenosis with or without fistula	25	0	1	4.21
Small intestine atresia/stenosis	21	0	0	3.40
Anorectal atresia/stenosis	25	0	2	4.37
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	6	0	0	0.97
Epispadias	2	0	0	0.32
Indeterminate sex	5	0	2	1.13
Renal agenesis	48	0	7	8.91
Cystic kidney	36	0	1	5.99
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	35	0	0	5.67
Total Limb reduction defects (include unspecified)	21	0	4	4.05
Transverse	14	0	2	2.59
Preaxial	4	0	0	0.65
Postaxial	3	0	0	0.49
Intercalary	0	0	0	0.00
Mixed	0	0	1	0.16
Unspecified	0	0	1	0.16
Diaphragmatic hernia	11	0	1	1.94
Omphalocele	3	0	5	1.30
Gastroschisis	0	0	2	0.32
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.16
Trisomy 13	0	0	4	0.65
Trisomy 18	3	0	13	2.59
Down syndrome, all ages (include age unknown)	59	0	81	22.68
<20	0	0	0	nc
20-24	1	0	1	nc
25-29	2	0	6	nc
30-34	8	0	16	nc
35-39	9	0	32	nc
40+	5	0	25	nc
unknown	34	0	1	---

nr = not reported
nc = not calculable

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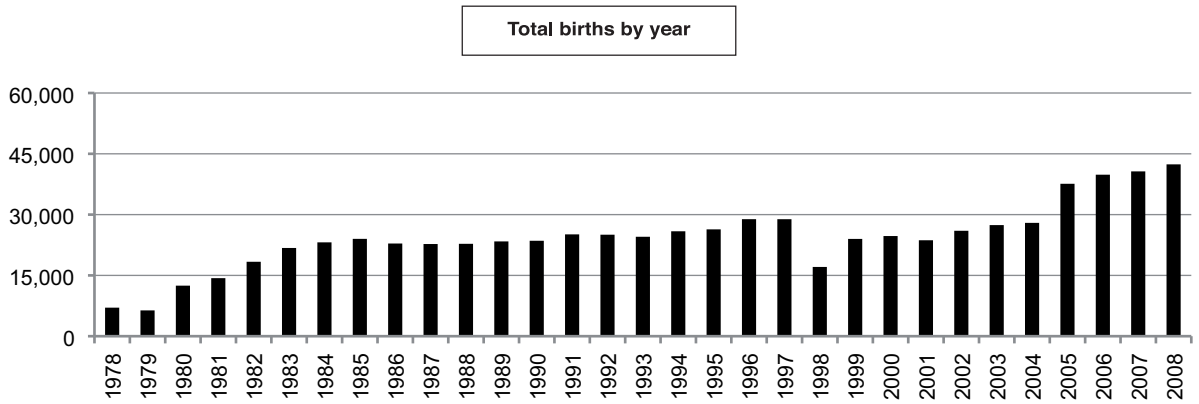
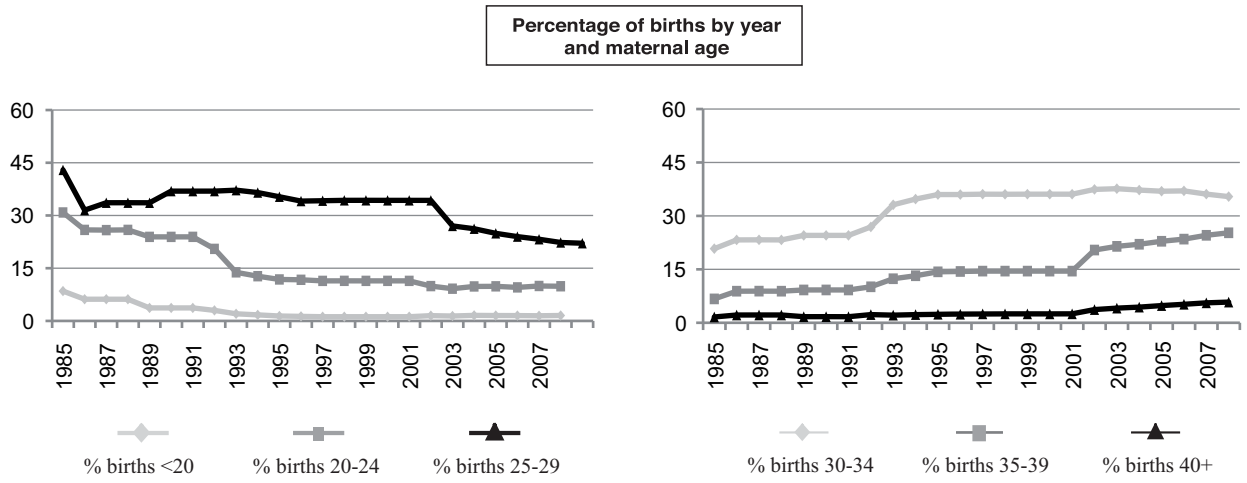
Centro per lo Studio delle Malformazioni Congenite
e Centro Malattie Rare
U.O. Neonatologia
Universita' di Bologna
Via Massarenti 11
40138 Bologna, Italy

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

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

Italy: IMER





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	21	84.0	Cystic kidney	20	40.8
Spina bifida	21	72.4	Limb reduction defects	15	23.8
Encephalocele	7	87.5	Diaphragmatic hernia	6	16.7
Holoprosencephaly	12	75.0	Omphalocele	15	62.5
Hydrocephaly	46	71.9	Gastroschisis	3	23.1
Hypoplastic left heart syndrome	16	51.6	Trisomy 13	17	89.5
Cleft palate without cleft lip	4	6.9	Trisomy 18	45	80.4
Cleft lip with or without cleft palate	16	19.3	Down syndrome	162	70.1
Renal agenesis	16	31.4			

Total ToPs with births defects = 591 (Ratio ToPs/Births: 4.81 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: IMER, 2008

Live births (LB)	42,287
Stillbirths (SB)	110
Total births	42,397
Number of terminations of pregnancy (ToP) for birth defects	210

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	11	2.59
Spina bifida	3	0	7	2.36
Encephalocele	1	0	3	0.94
Microcephaly	0	0	0	0.00
Holoprosencephaly	2	0	2	0.94
Hydrocephaly	8	0	12	4.72
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	0	0.47
Unspecified Anophthalmos/Microphthalmos	3	0	0	0.71
Anotia	3	0	0	0.71
Microtia	1	0	0	0.24
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	14	0	1	3.54
Tetralogy of Fallot	15	0	3	4.25
Hypoplastic left heart syndrome	2	0	4	1.42
Coarctation of aorta	10	0	0	2.36
Choanal atresia, bilateral	1	0	0	0.24
Cleft palate without cleft lip	16	0	0	3.77
Cleft lip with or without cleft palate	26	0	7	7.78
Oesophageal atresia/stenosis with or without fistula	7	0	1	1.89
Small intestine atresia/stenosis	4	0	0	0.94
Anorectal atresia/stenosis	6	0	3	2.12
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	67	0	1	16.04
Epispadias	0	0	0	0.00
Indeterminate sex	2	0	0	0.47
Renal agenesis	11	0	3	3.30
Cystic kidney	16	0	2	4.25
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	5	0	1	1.42
Total Limb reduction defects (include unspecified)	14	0	7	4.95
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	14	0	7	4.95
Diaphragmatic hernia	14	0	3	4.01
Omphalocele	3	0	6	2.12
Gastroschisis	5	0	0	1.18
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.24
Trisomy 13	0	0	6	1.42
Trisomy 18	3	2	14	4.48
Down syndrome, all ages (include age unknown)	24	0	60	19.81
<20	1	nr	0	15.38
20-24	2	nr	0	4.83
25-29	1	nr	4	5.38
30-34	1	nr	13	9.41
35-39	16	nr	28	41.46
40-44	2	nr	10	51.44
45+	0	nr	2	188.68
unknown	1	nr	3	---

nr = not reported

Italy: IMER, Previous years rates 1978 - 2008

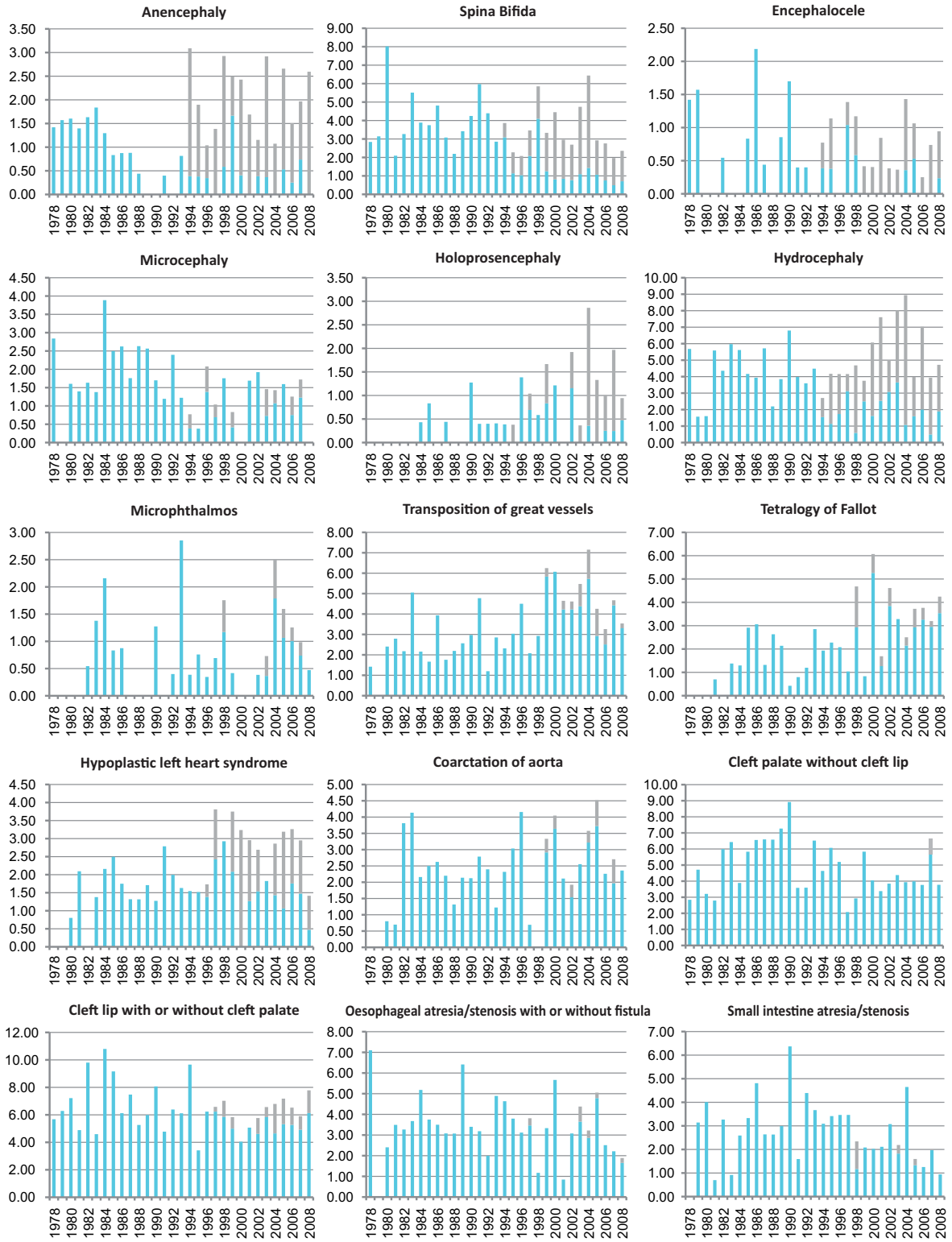
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978*	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**7,042**	**73,291**	**115,574**	**121,629**	**127,071**	**125,807**	**188,473**
Anencephaly	1.42	1.64	0.87	0.25	1.97	2.15	2.02
Spina bifida	2.84	4.50	3.55	4.19	3.31	3.66	3.08
Encephalocele	1.42	0.27	0.69	0.66	0.87	0.48	0.85
Microcephaly	2.84	1.36	2.68	1.81	1.18	1.19	1.17
Holoprosencephaly	0.00	0.00	0.35	0.49	0.79	1.03	1.54
Hydrocephaly	5.68	4.37	4.33	4.52	3.93	6.12	5.52
Anophthalmos	1.42	0.41	0.00	0.16	0.31	0.32	0.11
Microphthalmos	0.00	0.55	0.78	0.90	0.71	0.32	1.27
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.16
Anotia	nr	nr	nr	nr	0.63	0.64	1.01
Microtia	nr	nr	nr	nr	0.63	0.72	0.69
Unspecified Anotia / Microtia	nr	nr	nr	nr	0.00	0.00	0.00
Transposition of great vessels	1.42	3.00	2.34	2.88	2.99	5.41	4.40
Tetralogy of Fallot	nr	0.60*	2.25	1.48	2.20	3.34	3.55
Hypoplastic left heart syndrome	0.00	0.96	1.82	1.89	2.28	2.86	2.71
Coarctation of aorta	nr	2.69*	2.16	2.14	2.20	2.78	3.02
Choanal atresia, bilateral	0.00	0.27	0.17	0.41	0.00	0.56	0.27
Cleft palate without cleft lip	2.84	4.91	5.88	5.92	4.25	4.29	4.46
Cleft lip with or without cleft palate	5.68	6.55	7.79	6.25	6.53	5.48	6.84
Oesophageal atresia / stenosis with or without fistula	7.10	3.00	3.72	3.95	3.46	3.50	2.92
Small intestine atresia / stenosis	0.00	2.18	3.20	3.78	3.23	2.31	1.91
Anorectal atresia / stenosis	0.00	3.00	2.86	3.45	2.12	3.42	2.55
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	9.94	19.92	21.11	17.76	16.71*	17.01	14.70
Epispadias	nr	nr	nr	nr	0.00*	0.00	0.00
Indeterminate sex	nr	nr	nr	nr	0.20*	0.32	0.53
Renal agenesis	4.26	1.50	1.21	1.89	2.05	4.05	4.09
Cystic kidney	1.42	0.27	1.04	0.16	2.83	3.82	4.51
Bladder exstrophy	1.42	0.41	0.78	0.08	0.16	0.24	0.21
Polydactyly, preaxial	8.52	9.69	8.13	8.55	3.15	2.54	3.13
Total Limb reduction defects (include unspecified)	nr	nr	5.63*	5.59	4.09	4.21	5.57
Transverse	nr	nr	3.35*	2.96	1.89	1.75	2.09*
Preaxial	nr	nr	0.54*	0.90	0.94	0.56	1.61*
Postaxial	nr	nr	0.76*	0.49	0.24	0.79	0.47*
Intercalary	nr	nr	0.43*	0.82	0.39	0.64	0.38*
Mixed	nr	nr	0.22*	0.41	0.24	0.08	0.28*
Unspecified	nr	nr	0.32*	0.00	0.39	0.40	1.42*
Diaphragmatic hernia	0.00	1.23	2.16	2.71	2.68	3.42	3.50
Omphalocele	2.84	1.50	1.99	2.06	1.34	2.78	1.96
Gastroschisis	0.00	0.82	0.87	1.07	0.47	0.87	1.27
Unspecified Omphalocele / Gastroschisis	0.00	0.27	0.52	1.07	0.00	0.00	0.00
Prune belly sequence	0.00	0.27	0.52	0.25	0.31	0.32	0.05
Trisomy 13	0.00	1.77	0.78	0.66	1.02	1.51	1.64
Trisomy 18	1.42	1.09	0.95	0.90	1.81	4.37	4.56
Down syndrome, all ages (include age unknown)	21.30	13.51	13.50	12.91	19.52	17.96	19.26
<20	nr	nr	1.60*	7.67	5.74	12.19	14.01
20-24	nr	nr	5.97*	4.27	8.65	8.25	3.82
25-29	nr	nr	11.45*	8.03	8.22	4.87	5.76
30-34	nr	nr	11.96*	16.91	12.10	14.08	9.82
35-39	nr	nr	37.79*	30.35	44.98	34.13	37.55
40-44	nr	nr	75.71*	58.93	188.49	114.24	83.64
45+	nr	nr	59.88*	80.65	133.33	220.59	112.36
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

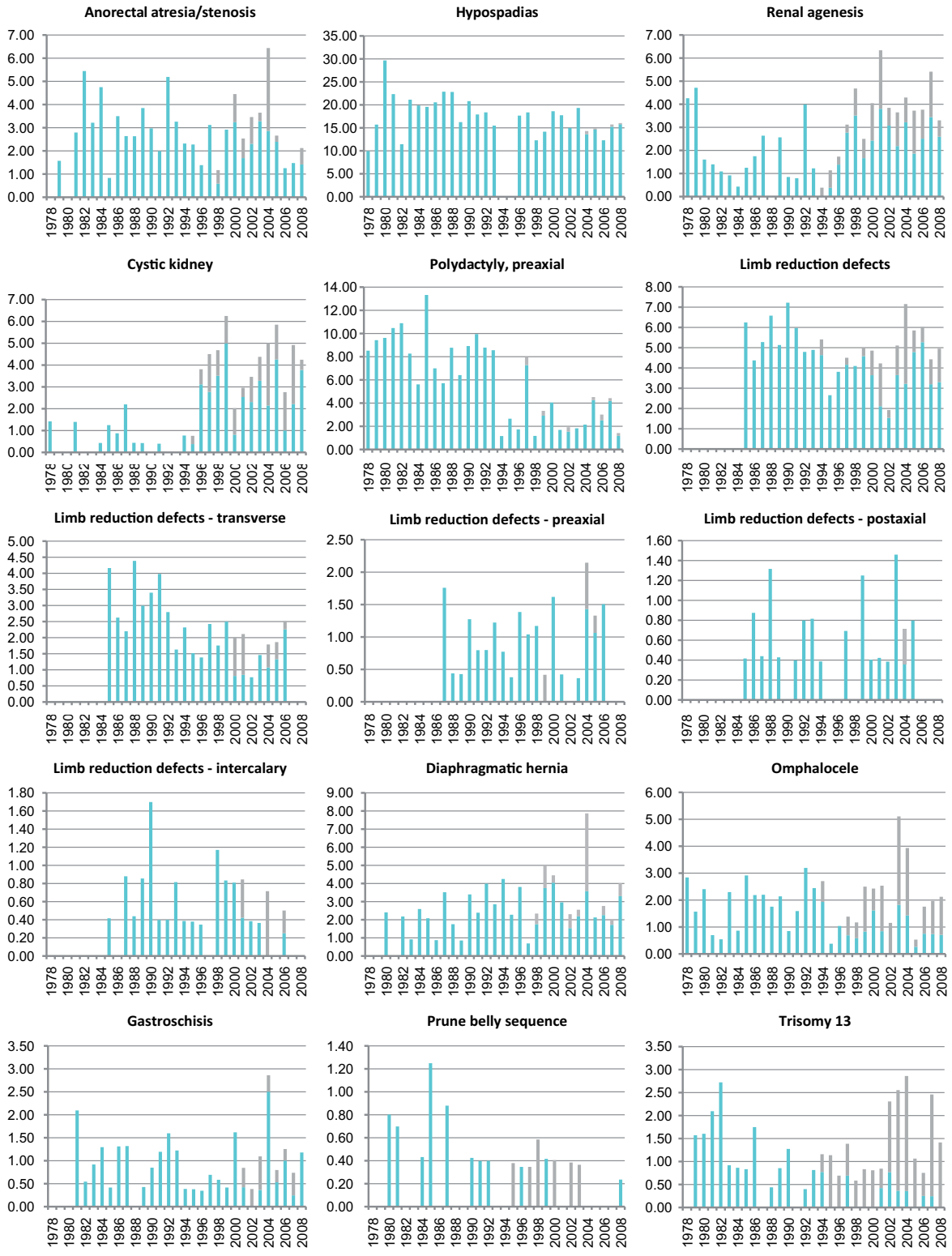
Italy: IMER

Time trends 1978-2008 (Birth prevalence rates per 10,000)



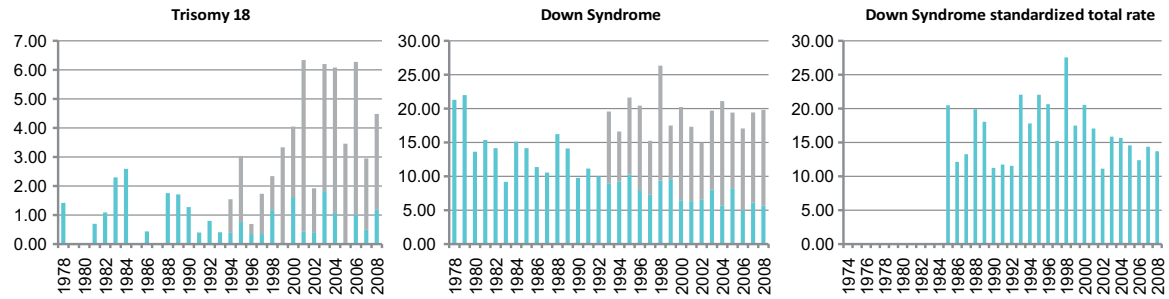
Note: L+S rates, ToP rates

Italy: IMER



Note: L+S rates, ToP rates

Italy: IMER



Note: L+S rates, ToP rates

ITALY - Lombardy: CMRL
Italy LMCR Registry of Congenital Malformations

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 16 600 births annually, constituting 100% of the total annual births in the Provinces of Sondrio, Varese and the northern part of Milan (HLA1). This is about 18.2% of the total annual births in the Region of Lombardy, and the 3.1% 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.

Addresses and Staff:
Programme Directors:
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Paolo Contiero PhD
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Roberto Tessandori, Sabrina Fabiano, Lucia Preto, Anna Maghini, Daniele Vergani, Andrea Tittarelli

Congenital Malformation Registry of Northern Lombardy (CMRL)
National Cancer Institute
Via Venezian 1, 20133 Milan, Italy
Phone: 39-02 23903539

ITALY - Lombardy: CMRL, 2008*

Live births (LB)	5,751
Stillbirths (SB)	22
Total births	5,773
Number of terminations of pregnancy (ToP) for birth defects	16

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	1	1.73
Spina bifida	1	0	0	1.73
Encephalocele	0	0	0	0.00
Microcephaly	0	0	0	0.00
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	0	0	0	0.00
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	1.73
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	1	0	0	1.73
Tetralogy of Fallot	2	0	0	3.46
Hypoplastic left heart syndrome	0	0	0	0.00
Coarctation of aorta	5	0	0	8.66
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	5	0	0	8.66
Cleft lip with or without cleft palate	3	0	0	5.20
Oesophageal atresia/stenosis with or without fistula	1	0	0	1.73
Small intestine atresia/stenosis	0	0	0	0.00
Anorectal atresia/stenosis	3	0	0	5.20
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	22	0	0	38.11
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	0	0	0	0.00
Cystic kidney	3	0	0	5.20
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	1	0	0	1.73
Total Limb reduction defects (include unspecified)	8	0	0	13.86
Transverse	5	0	0	8.66
Preaxial	0	0	0	0.00
Postaxial	1	0	0	1.73
Intercalary	1	0	0	1.73
Mixed	0	0	0	0.00
Unspecified	1	0	0	1.73
Diaphragmatic hernia	0	0	0	0.00
Omphalocele	0	0	0	0.00
Gastroschisis	0	0	0	0.00
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	2	3.46
Down syndrome, all ages (include age unknown)	0	0	0	0.00
<20	0	0	0	0.00
20-24	0	0	0	0.00
25-29	0	0	0	0.00
30-34	1	0	1	8.85
35-39	2	0	2	26.40
40-44	3	0	1	123.08
45+	1	0	0	555.56
unknown	0	0	0	---

* data for the province of Como

Italy - Tuscany: RTDC
Tuscany Registry of Congenital Defects

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

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

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

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

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

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

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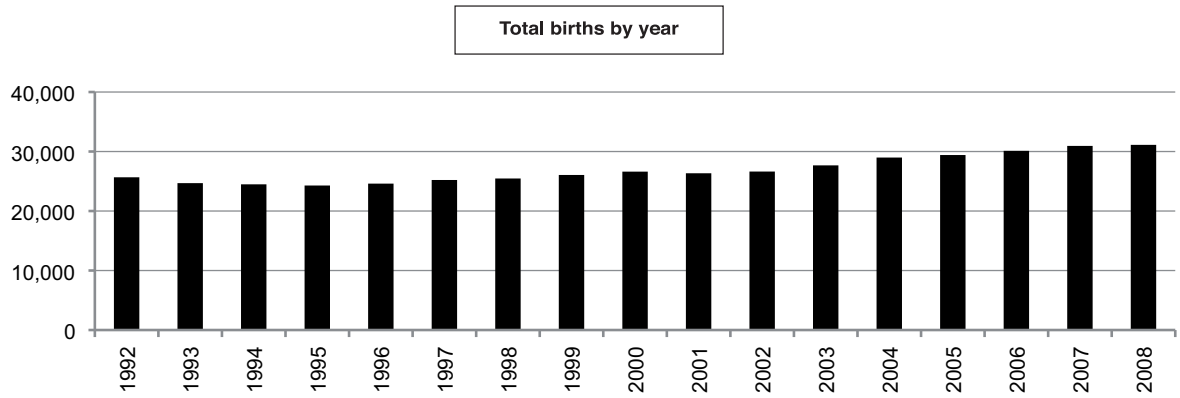
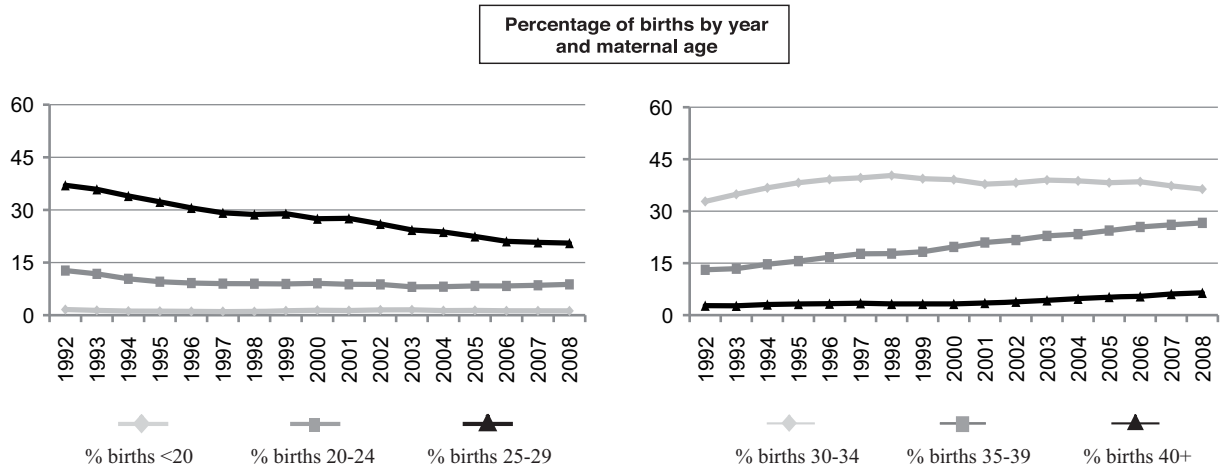
Italy - Tuscany: RTDC





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	17	89.5	Cystic kidney	9	22.5
Spina bifida	20	80.0	Limb reduction defects	10	25.6
Encephalocele	5	62.5	Diaphragmatic hernia	4	25.0
Holoprosencephaly	9	90.0	Omphalocele	15	75.0
Hydrocephaly	22	75.9	Gastroschisis	4	36.4
Hypoplastic left heart syndrome	6	33.3	Trisomy 13	16	88.9
Cleft palate without cleft lip	3	10.7	Trisomy 18	29	85.3
Cleft lip with or without cleft palate	11	26.8	Down syndrome	104	68.0
Renal agenesis	7	77.8			

Total ToPs with births defects = 372 (Ratio ToPs/Births: 4.04 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy - Tuscany: RTDC, 2008

Live births (LB)	31,037
Stillbirths (SB)	83
Total births	31,120
Number of terminations of pregnancy (ToP) for birth defects	129

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	5	1.61
Spina bifida	2	0	7	2.89
Encephalocele	1	0	2	0.96
Microcephaly	1	0	0	0.32
Holoprosencephaly	0	0	1	0.32
Hydrocephaly	1	0	6	2.25
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	0	0.64
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.64
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	10	0	2	3.86
Tetralogy of Fallot	8	0	0	2.57
Hypoplastic left heart syndrome	3	0	3	1.93
Coarctation of aorta	5	0	0	1.61
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	8	0	2	3.21
Cleft lip with or without cleft palate	13	0	3	5.14
Oesophageal atresia/stenosis with or without fistula	8	0	0	2.57
Small intestine atresia/stenosis	3	0	0	0.96
Anorectal atresia/stenosis	6	0	3	2.89
Undescended testis (36 weeks of gestation or later)	24	0	0	7.71
Hypospadias	50	0	0	16.07
Epispadias	0	0	1	0.32
Indeterminate sex	2	0	2	1.29
Renal agenesis	0	0	5	1.61
Cystic kidney	7	0	4	3.53
Bladder exstrophy	0	0	1	0.32
Polydactyly, preaxial	1	0	2	0.96
Total Limb reduction defects (include unspecified)	8	0	4	3.86
Transverse	7	0	3	3.21
Preaxial	0	0	1	0.32
Postaxial	1	0	0	0.32
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	1	0	0	0.32
Diaphragmatic hernia	4	0	1	1.61
Omphalocele	1	0	6	2.25
Gastroschisis	2	0	0	0.64
Unspecified Omphalocele/Gastroschisis	1	0	1	0.64
Prune belly sequence	1	0	1	0.64
Trisomy 13	0	0	6	1.93
Trisomy 18	2	0	13	4.82
Down syndrome, all ages (include age unknown)	20	0	38	18.64
<20	0	0	0	0.00
20-24	1	0	1	7.32
25-29	0	0	4	6.26
30-34	5	0	2	6.19
35-39	7	0	14	25.37
40-44	4	0	16	105.10
45+	2	0	0	202.02
unknown	1	0	1	---

Italy - Tuscany: RTDC, Previous years rates 1992 - 2008

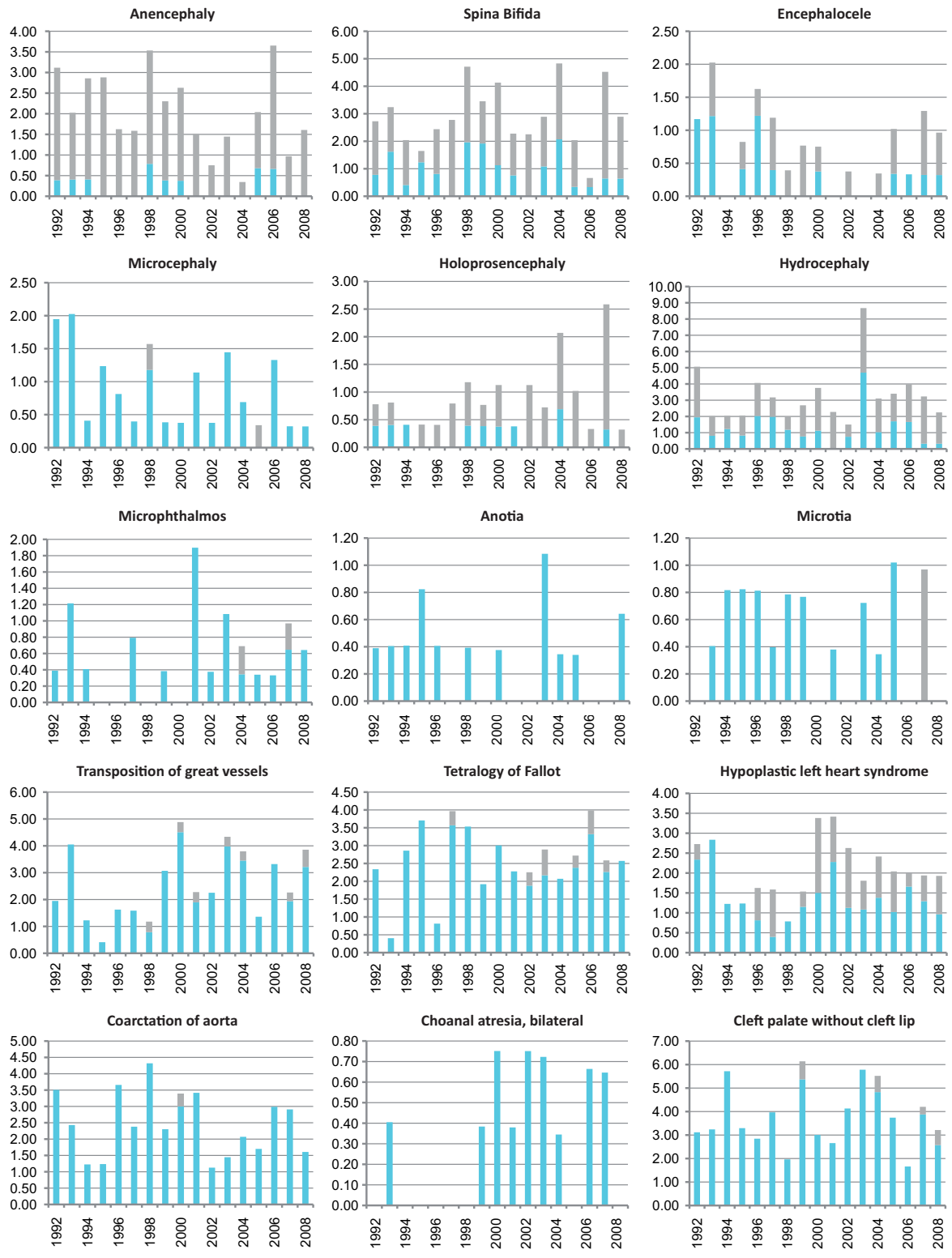
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-19881989-1993*	1994-1998	1999-2003	2004-2008
Total births			**50,357**	**124,065**	**133,334**	**150,578**
Anencephaly			2.58	2.50	1.72	1.73
Spina bifida			2.98	2.74	3.00	2.99
Encephalocele			1.59	0.81	0.37	0.80
Microcephaly			1.99	0.89	0.75	0.60
Holoprosencephaly			0.79	0.64	0.82	1.26
Hydrocephaly			3.57	2.66	3.82	3.19
Anophthalmos			0.00	0.08	0.22	0.13
Microphthalmos			0.79	0.24	0.75	0.60
Unspecified Anophthalmos / Microphthalmos			0.00	0.00	0.07	0.00
Anotia			0.40	0.40	0.30	0.27
Microtia			0.20	0.73	0.37	0.46
Unspecified Anotia / Microtia			0.00	0.00	0.00	0.00
Transposition of great vessels			2.98	1.21	3.37	2.92
Tetralogy of Fallot			1.39	2.98	2.47	2.79
Hypoplastic left heart syndrome			2.78	1.29	2.55	2.06
Coarctation of aorta			2.98	2.58	2.32	2.26
Choanal atresia, bilateral			0.20	0.00	0.60	0.33
Cleft palate without cleft lip			3.18	3.55	4.35	3.65
Cleft lip with or without cleft palate			10.13	5.32	6.90	4.91
Oesophageal atresia / stenosis with or without fistula			2.18	2.58	2.25	2.06
Small intestine atresia / stenosis			0.99	0.73	1.05	1.13
Anorectal atresia / stenosis			1.19	1.69	3.00	1.99
Undescended testis (36 weeks of gestation or later)			2.78	5.24	11.47	4.65
Hypospadias			6.16	3.47	6.22	8.50
Epispadias			0.20	0.32	0.15	0.27
Indeterminate sex			0.20	1.05	0.60	0.46
Renal agenesis			1.79	1.77	0.82	0.86
Cystic kidney			2.38	3.87	3.82	4.18
Bladder exstrophy			0.60	0.16	0.22	0.27
Polydactyly, preaxial			0.99	0.81	1.35	1.06
Total Limb reduction defects (include unspecified)			5.36	4.67	5.92	4.91
Transverse			3.97	2.74	4.05	2.72
Preaxial			0.20	0.24	0.67	0.40
Postaxial			0.20	0.24	0.22	0.27
Intercalary			0.40	0.56	0.45	0.27
Mixed			0.20	0.56	0.30	0.07
Unspecified			0.40	0.32	0.45	1.46
Diaphragmatic hernia			1.39	1.53	2.02	1.66
Omphalocele			2.38	1.29	1.95	1.86
Gastroschisis			0.79	0.16	0.52	1.06
Unspecified Omphalocele / Gastroschisis			0.60	0.24	0.30	0.13
Prune belly sequence			0.20	0.16	0.00	0.13
Trisomy 13			0.40	0.73	0.97	1.73
Trisomy 18			2.58	3.39	2.55	3.52
Down syndrome, all ages (include age unknown)			12.31	16.60	15.97	16.54
<20			0.00	0.00	0.00	0.00
20-24			1.64	9.65	4.34	4.76
25-29			9.37	8.27	4.51	4.01
30-34			8.92	13.16	10.75	5.83
35-39			30.36	29.45	23.72	27.55
40-44			47.39	107.47	145.37	95.36
45+			235.29	88.50	105.26	127.80
unknown			---	---	---	---

* data include only 1 year

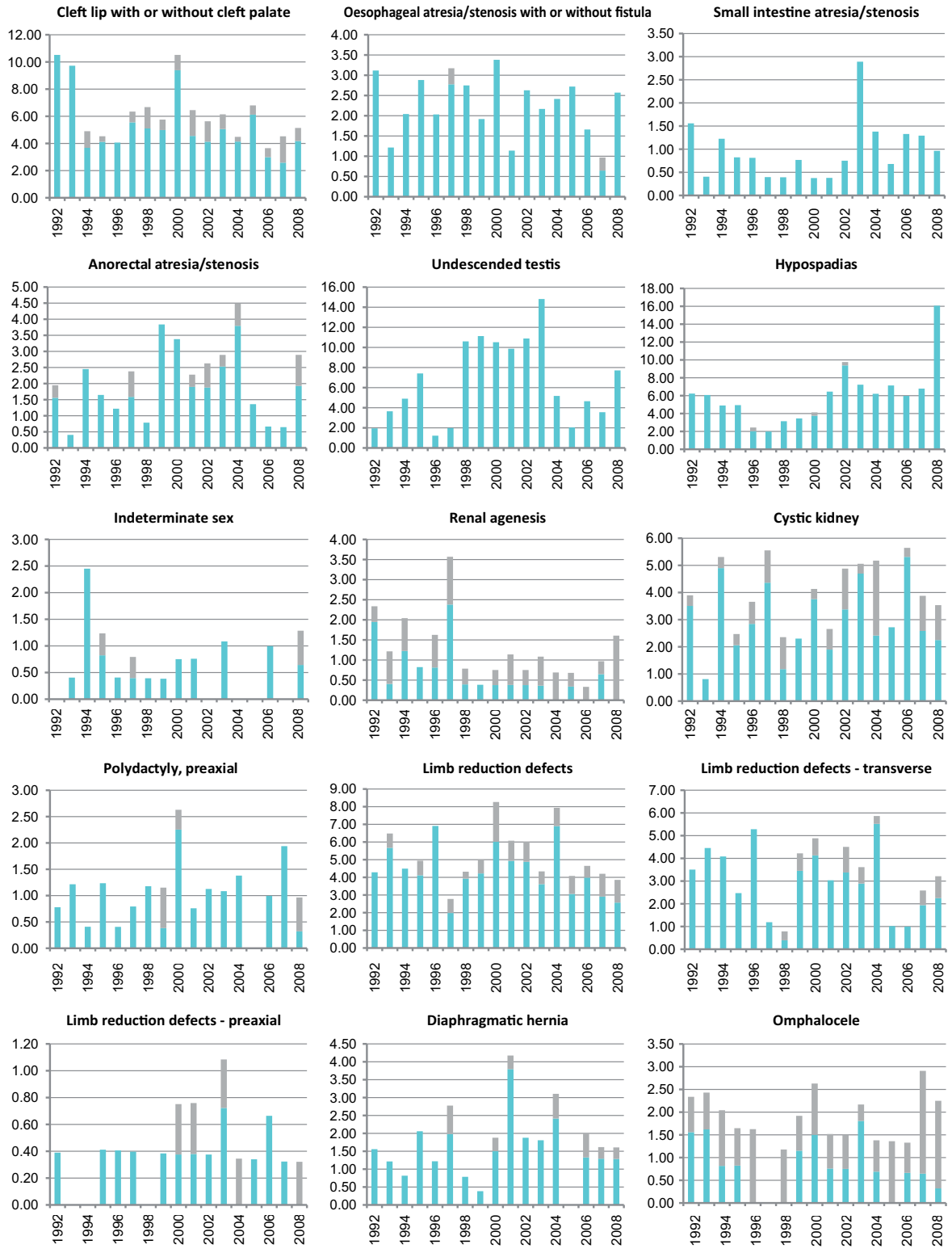
Italy - Tuscany: RTDC

Time trends 1992-2008 (Birth prevalence rates per 10,000)



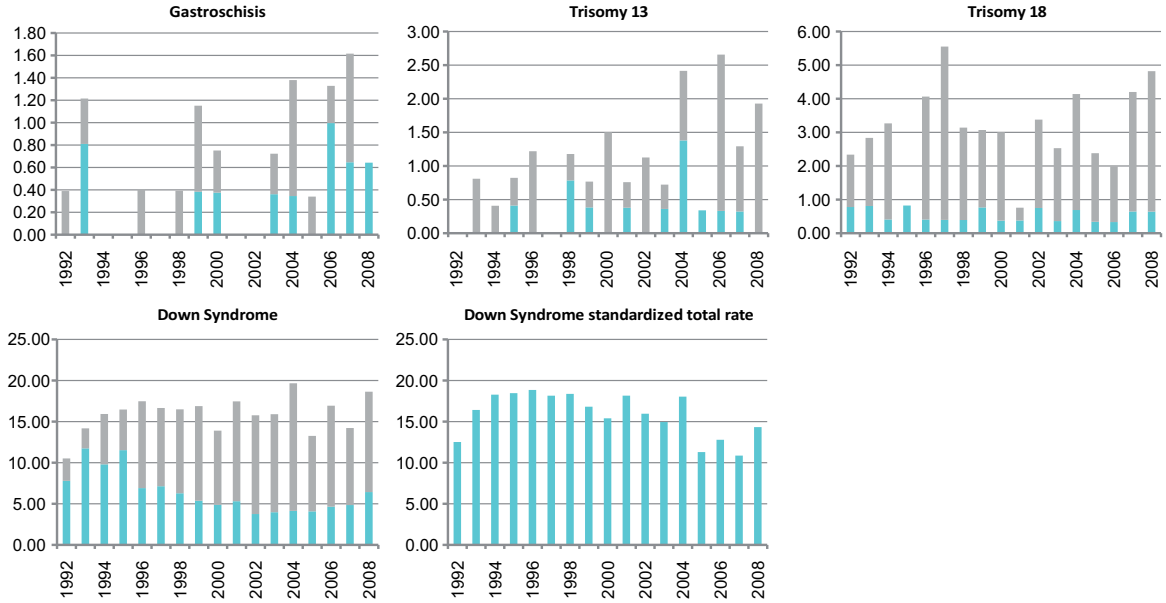
Note: L+S rates, ToP rates

Italy - Tuscany: RTDC



Note: L+S rates, ToP rates

Italy - Tuscany: RTDC



Note: L+S rates, ToP rates

Japan: JAOG
Japan Association of Obstetricians and Gynaecologists

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

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

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

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

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

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

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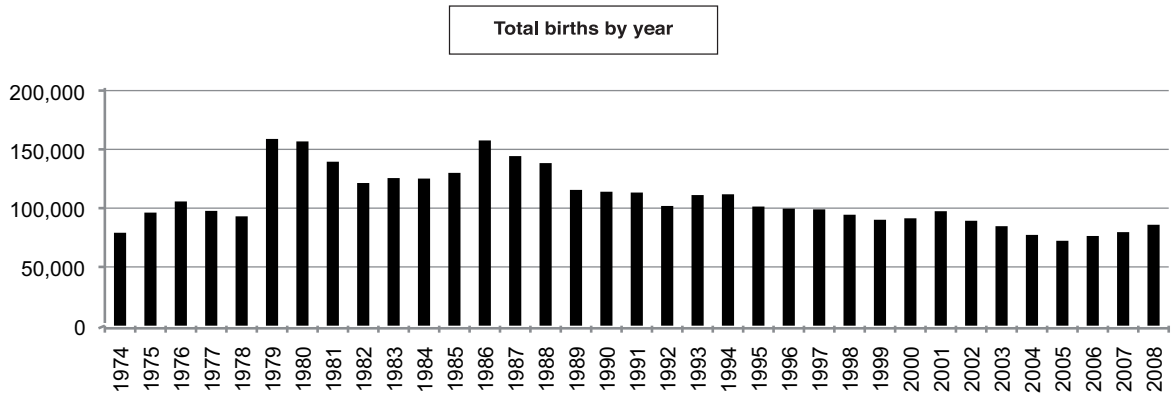
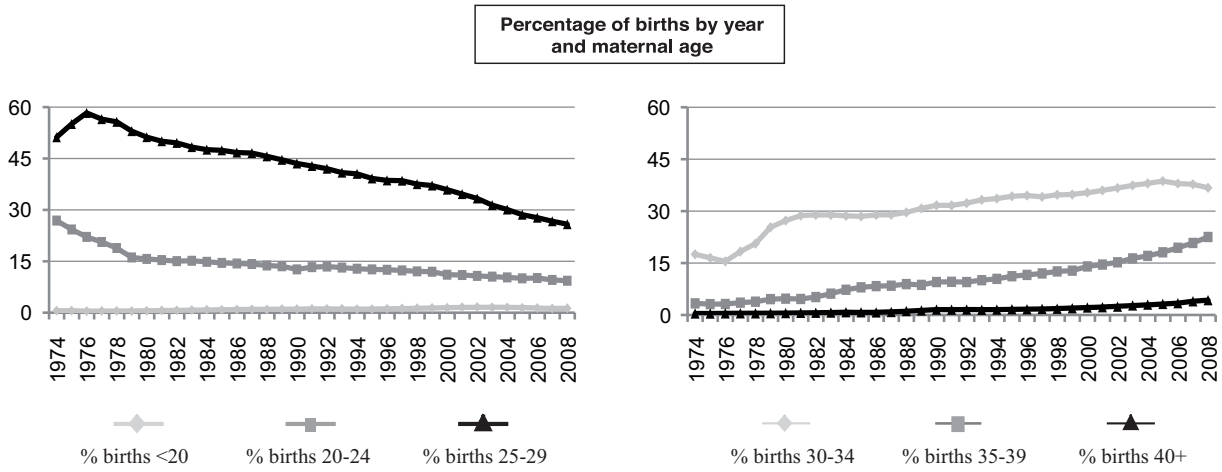
Fax: 81-45-787-2689
E-mail: hirafu@med.yokohama-cu.ac.jp

Japan: JAOG


Total births by year
200,000
150,000
100,000
50,000
0
1974 1975 1976 1977 1978 1979 1980 1981 1982 1983 1984 1985 1986 1987 1988 1989 1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008


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
% births 30-34
% births 35-39
% births 40+

Japan JAOG, 2008

Live births (LB)	85,324
Stillbirths (SB)	531
Total births	85,855
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	7	4	nr	1.28
Spina bifida	44	2	nr	5.36
Encephalocele	5	0	nr	0.58
Microcephaly	13	2	nr	1.75
Holoprosencephaly	9	3	nr	1.40
Hydrocephaly	69	4	nr	8.50
Anophthalmos	2	0	nr	0.23
Microphthalmos	5	0	nr	0.58
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	0	0	nr	0.00
Microtia	11	2	nr	1.51
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	31	1	nr	3.73
Tetralogy of Fallot	47	1	nr	5.59
Hypoplastic left heart syndrome	27	5	nr	3.73
Coarctation of aorta	44	4	nr	5.59
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	27	2	nr	3.38
Cleft lip with or without cleft palate	179	17	nr	22.83
Oesophageal atresia/stenosis with or without fistula	32	0	nr	3.73
Small intestine atresia/stenosis	55	1	nr	6.52
Anorectal atresia/stenosis	47	1	nr	5.59
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	47	0	nr	5.47
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	16	7	nr	2.68
Cystic kidney	31	5	nr	4.19
Bladder exstrophy	2	0	nr	0.23
Polydactyly, preaxial	52	2	nr	6.29
Total Limb reduction defects (include unspecified)	24	6	nr	3.49
Transverse	1	1	nr	0.23
Preaxial	7	2	nr	1.05
Postaxial	4	0	nr	0.47
Intercalary	8	1	nr	1.05
Mixed	3	0	nr	0.35
Unspecified	1	2	nr	0.35
Diaphragmatic hernia	42	4	nr	5.36
Omphalocele	23	8	nr	3.61
Gastroschisis	25	2	nr	3.14
Unspecified Omphalocele/Gastroschisis	3	0	nr	0.35
Prune belly sequence	1	0	nr	0.12
Trisomy 13	11	8	nr	2.21
Trisomy 18	54	23	nr	8.97
Down syndrome, all ages (include age unknown)	102	8	nr	12.81
<20	0	0	nr	0.00
20-24	4	1	nr	6.24
25-29	14	0	nr	6.31
30-34	22	3	nr	7.93
35-39	46	2	nr	24.81
40+	16	2	nr	48.98
unknown	0	0	nr	---

nr = not reported

Japan: JAOG, Previous years rates 1974 - 2008

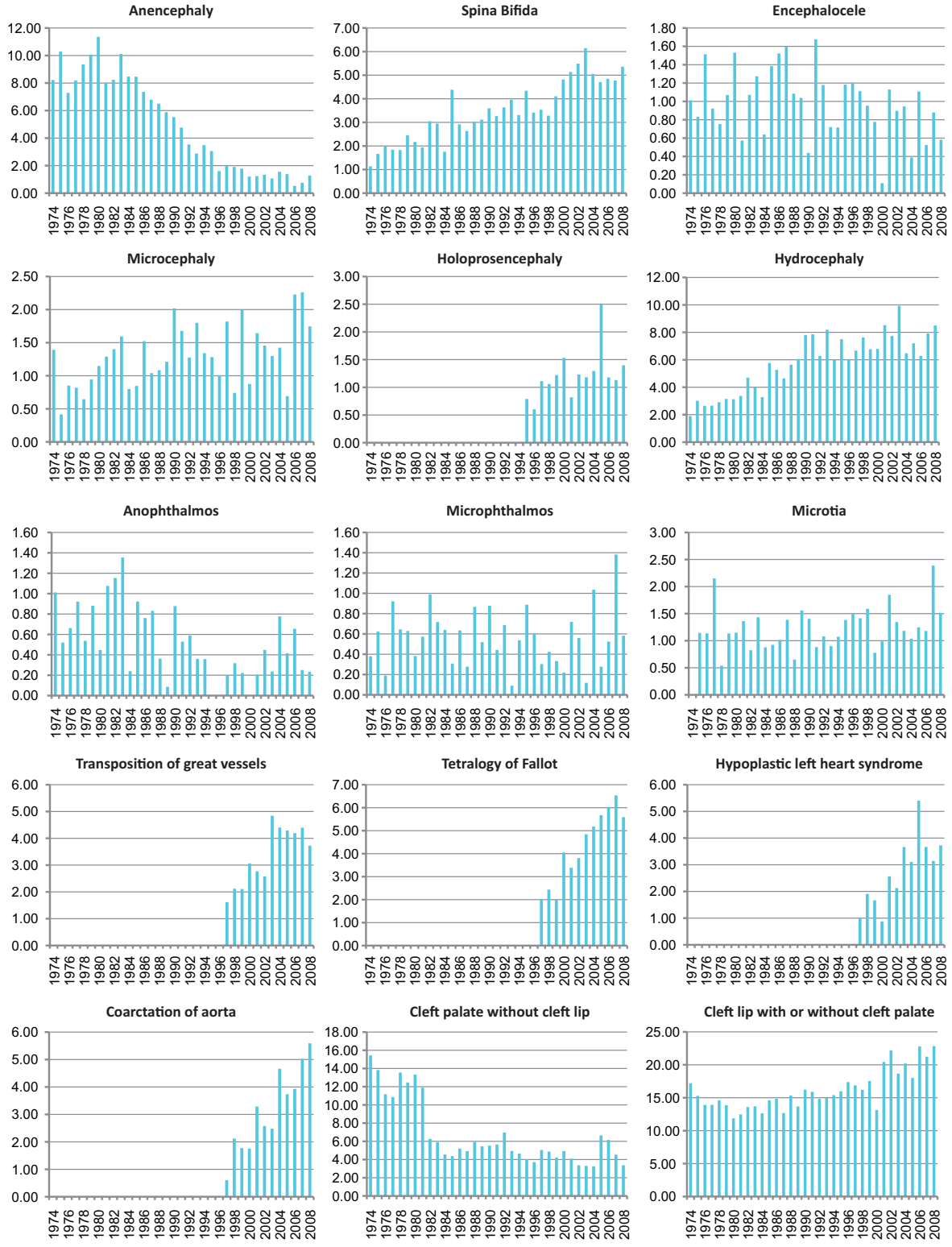
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**471,634**	**702,082**	**695,332**	**555,726**	**506,077**	**452,752**	**391,227**
Anencephaly	8.65	9.64	7.48	4.55	2.45	1.33	1.10
Spina bifida	1.72	2.48	2.95	3.51	3.58	5.12	4.96
Encephalocele	1.02	1.11	1.27	1.01	1.03	0.77	0.69
Microcephaly	0.81	1.25	1.08	1.60	1.24	1.46	1.69
Holoprosencephaly	nr	nr	nr	nr	0.89*	1.19	1.48
Hydrocephaly	2.65	3.60	4.95	7.25	6.74	7.93	7.31
Anophthalmos	0.72	0.95	0.63	0.49	0.18	0.22	0.46
Microphthalmos	0.55	0.64	0.55	0.52	0.55	0.40	0.77
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	1.04	1.18	0.98	1.17	1.38	1.24	1.48
Unspecified Anotia / Microtia	nr	nr	nr	nr	nr	nr	0.00*
Transposition of great vessels	nr	nr	nr	nr	1.86*	3.05	4.19
Tetralogy of Fallot	nr	nr	nr	nr	2.22*	3.60	5.80
Hypoplastic left heart syndrome	nr	nr	nr	nr	1.45*	2.16	3.78
Coarctation of aorta	nr	nr	nr	nr	1.34*	2.39	4.63
Choanal atresia, bilateral	nr	nr	nr	nr	nr	nr	0.00*
Cleft palate without cleft lip	12.83	10.30	5.02	5.69	4.47	4.00	4.73
Cleft lip with or without cleft palate	14.88	13.06	14.05	15.12	16.34	18.40	21.09
Oesophageal atresia / stenosis with or without fistula	0.75*	1.18	1.45	2.03	2.63	3.98	4.93
Small intestine atresia / stenosis	nr	nr	nr	nr	3.98*	5.74	6.80
Anorectal atresia / stenosis	4.03	3.90	3.87	4.34	4.15	5.17	6.31
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	0.00*
Hypospadias	1.61	2.19	2.36	2.90	2.96	3.98	4.06
Epispadias	nr	nr	nr	nr	nr	nr	0.00*
Indeterminate sex	nr	nr	nr	nr	nr	nr	0.00
Renal agenesis	nr	nr	nr	1.40	1.34	2.12	2.45
Cystic kidney	nr	nr	nr	nr	2.28*	4.40	3.96
Bladder exstrophy	0.10*	0.20	0.14	0.14	0.14	0.27	0.20
Polydactyly, preaxial	nr	nr	nr	6.21	6.26	6.36	6.65
Total Limb reduction defects (include unspecified)	nr	nr	nr	3.24*	3.46	3.29	3.37
Transverse	nr	nr	nr	0.45*	0.36	0.29	0.31
Preaxial	nr	nr	nr	0.45*	0.55	0.66	0.61
Postaxial	nr	nr	nr	0.09*	0.34	0.27	0.51
Intercalary	nr	nr	nr	1.62*	1.21	0.88	0.61
Mixed	nr	nr	nr	0.27*	0.63	0.73	0.92
Unspecified	nr	nr	nr	0.36*	0.38	0.46	0.41
Diaphragmatic hernia	nr	nr	nr	2.75	3.30	6.10	5.50
Omphalocele	0.98	1.38	2.33	3.19	3.44	3.27	3.89
Gastroschisis	1.21	0.81	1.06	1.64	1.62	2.52	2.61
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.38	0.22	0.38	0.15
Prune belly sequence	nr	nr	nr	nr	0.05*	0.02	0.05
Trisomy 13	nr	nr	nr	nr	0.77	0.97	2.22
Trisomy 18	nr	nr	nr	nr	3.18	6.60	8.49
Down syndrome, all ages (include age unknown)	2.79*	4.87	5.25	6.26	7.96	8.97	11.73
<20	nr	nr	nr	0.00*	3.49	7.24	1.88
20-24	nr	nr	nr	0.68*	3.80	2.20	4.41
25-29	nr	nr	nr	3.96*	4.87	4.99	5.90
30-34	nr	nr	nr	5.68*	7.56	7.97	9.33
35-39	nr	nr	nr	17.01*	18.02	19.11	21.82
40+	nr	nr	nr	53.86*	52.71	53.82	47.68
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

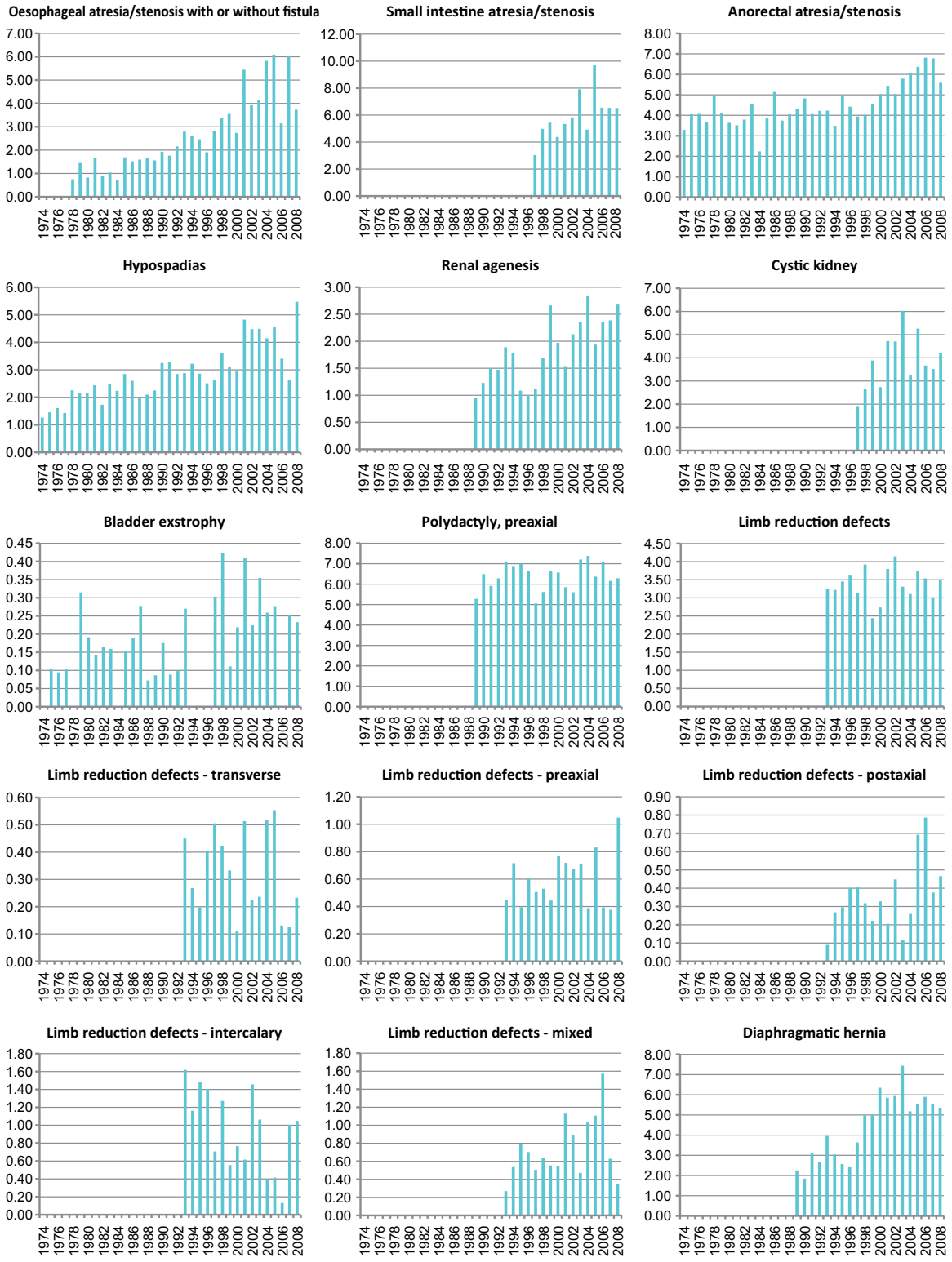
Japan: JAOG

Time trends 1974-2008 (Birth prevalence rates per 10,000)



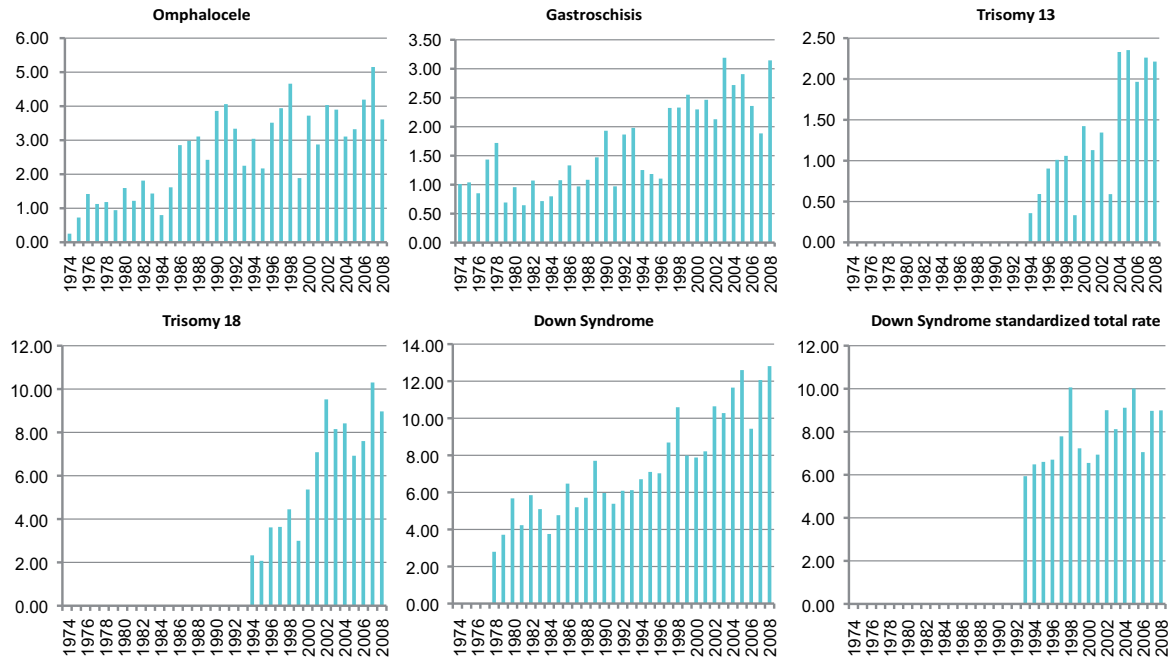
Note: L+S rates

Japan: JAOG



Note: L+S rates

Japan: JAOG



Note: L+S rates

Malta: MCAR
Malta Congenital Anomalies Register

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

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

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

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

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

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

Addresses and Staff:
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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
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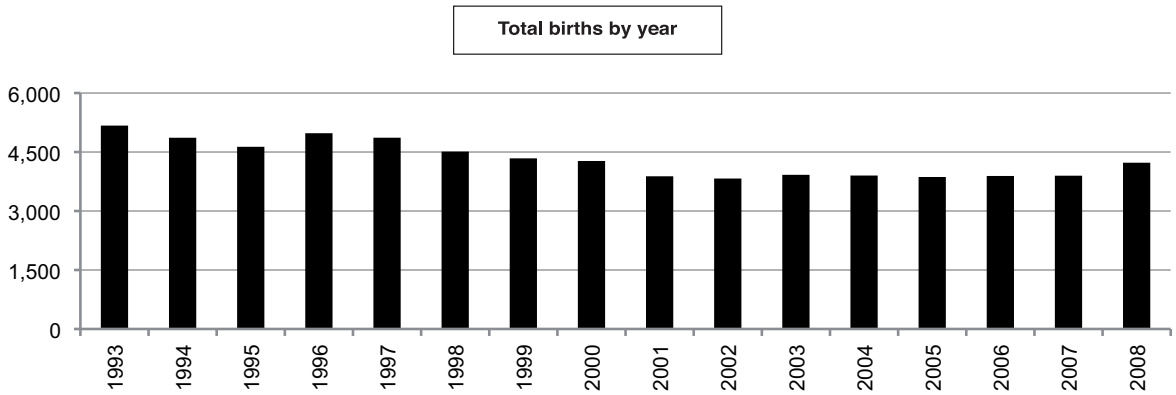
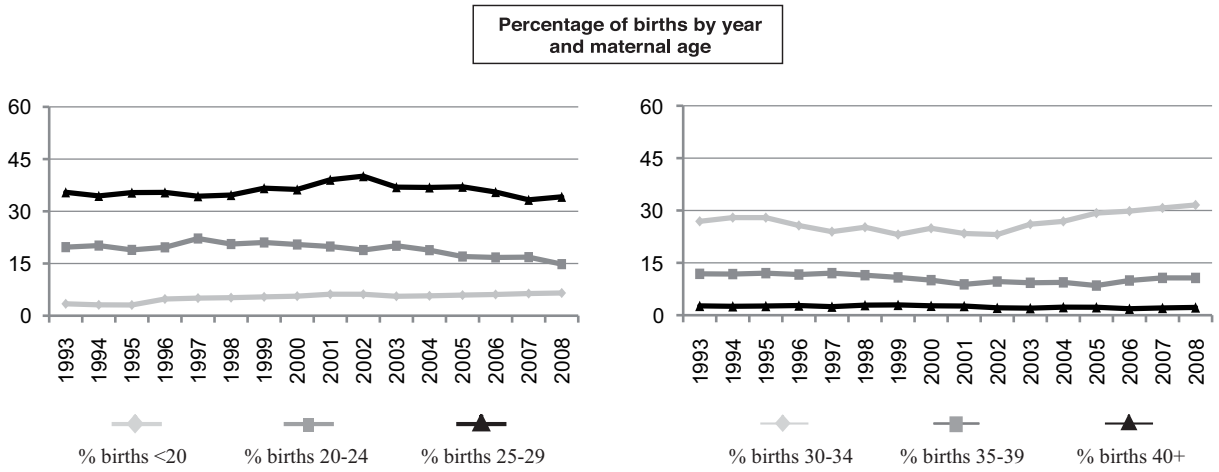
Malta: MCAR


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


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

Malta: MCAR, 2008

Live births (LB)	4,199
Stillbirths (SB)	29
Total births	4,228
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0		2.37
Spina bifida	3	1		9.46
Encephalocele	0	1		2.37
Microcephaly	1	1		4.73
Holoprosencephaly	0	0		0.00
Hydrocephaly	2	0		4.73
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	1		4.73
Tetralogy of Fallot	1	0		2.37
Hypoplastic left heart syndrome	2	1		7.10
Coarctation of aorta	3	0		7.10
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	8	0		18.92
Cleft lip with or without cleft palate	7	1		18.92
Oesophageal atresia/stenosis with or without fistula	0	0		0.00
Small intestine atresia/stenosis	1	0		2.37
Anorectal atresia/stenosis	2	0		4.73
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	16	0		37.84
Epispadias	0	0		0.00
Indeterminate sex	1	1		4.73
Renal agenesis	0	0		0.00
Cystic kidney	2	0		4.73
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	9	0		21.29
Total Limb reduction defects (include unspecified)	2	2		9.46
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	2	2		9.46
Diaphragmatic hernia	6	0		14.19
Omphalocele	1	0		2.37
Gastroschisis	0	0		0.00
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	nr	0		0.00
Trisomy 13	0	0		0.00
Trisomy 18	2	0		4.73
Down syndrome, all ages (include age unknown)	9	0		21.29
<20	1	0		36.23
20-24	1	0		15.97
25-29	1	0		6.93
30-34	1	0		7.50
35-39	2	0		44.35
40-44	3	0		340.91
45+	0	0		0.00
unknown	0	0		---

nr = not reported

Malta: MCAR, Previous years rates 1993 - 2008

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

	1974-1978	1979-1983	1984-1988	1989-1993*	1994-1998	1999-2003	2004-2008
Total births				**5,172**	**23,849**	**20,240**	**19,784**
Anencephaly				1.93	4.61	2.47	1.52
Spina bifida				7.73	7.13	5.43	7.58
Encephalocele				1.93	1.68	2.47	2.02
Microcephaly				3.87	3.35	4.45	4.04
Holoprosencephaly				0.00	1.26	0.99	0.51
Hydrocephaly				1.93	7.97	1.98	4.04
Anophthalmos				0.00	0.42	0.00	0.00
Microphthalmos				0.00	1.26	0.99	0.51
Unspecified Anophthalmos / Microphthalmos				0.00	0.00	0.00	0.00
Anotia				0.00	0.00	0.00	0.00
Microtia				0.00	0.00	0.00	0.00
Unspecified Anotia / Microtia				0.00	0.00	0.00	0.00
Transposition of great vessels				3.87	4.19	4.45	6.07
Tetralogy of Fallot				3.87	3.77	3.46	4.55
Hypoplastic left heart syndrome				1.93	0.84	3.95	3.54
Coarctation of aorta				3.87	6.29	4.45	5.56
Choanal atresia, bilateral				1.93	1.68	0.99	0.51
Cleft palate without cleft lip				15.47	13.84	10.87	16.17
Cleft lip with or without cleft palate				9.67	7.97	10.38	10.11
Oesophageal atresia / stenosis with or without fistula				1.93	1.26	2.47	2.02
Small intestine atresia / stenosis				0.00	1.26	2.47	1.52
Anorectal atresia / stenosis				3.87	4.19	5.43	3.54
Undescended testis (36 weeks of gestation or later)				nr	nr	nr	nr
Hypospadias				21.27	15.93	43.48	33.36
Epispadias				1.93	1.26	0.00	0.00
Indeterminate sex				1.93	0.84	0.99	2.53
Renal agenesis				3.87	2.94	3.95	4.04
Cystic kidney				1.93	5.03	1.98	3.03
Bladder exstrophy				0.00	0.00	0.00	0.00
Polydactyly, preaxial				15.47	15.51	17.79	14.15
Total Limb reduction defects (include unspecified)				5.80	5.45	7.41	6.57
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				5.80	5.45	7.41	6.57
Diaphragmatic hernia				1.93	6.71	4.94	5.05
Omphalocele				1.93	2.94	0.99	3.03
Gastroschisis				3.87	0.42	0.99	1.01
Unspecified Omphalocele / Gastroschisis				0.00	0.00	0.00	0.00
Prune belly sequence				1.93	0.42	0.00	0.00
Trisomy 13				0.00	0.00	0.49	1.01
Trisomy 18				0.00	3.77	3.95	3.54
Down syndrome, all ages (include age unknown)				29.00	14.26	22.23	18.70
<20				0.00	0.00	17.09	16.49
20-24				0.00	0.00	0.00	6.02
25-29				5.45	3.61	10.47	5.72
30-34				21.57	17.64	26.63	10.23
35-39				114.19	46.20	65.82	61.60
40-44				312.50	99.83	182.93	224.44
45+				0.00	312.50	0.00	833.33
unknown				---	---	---	---

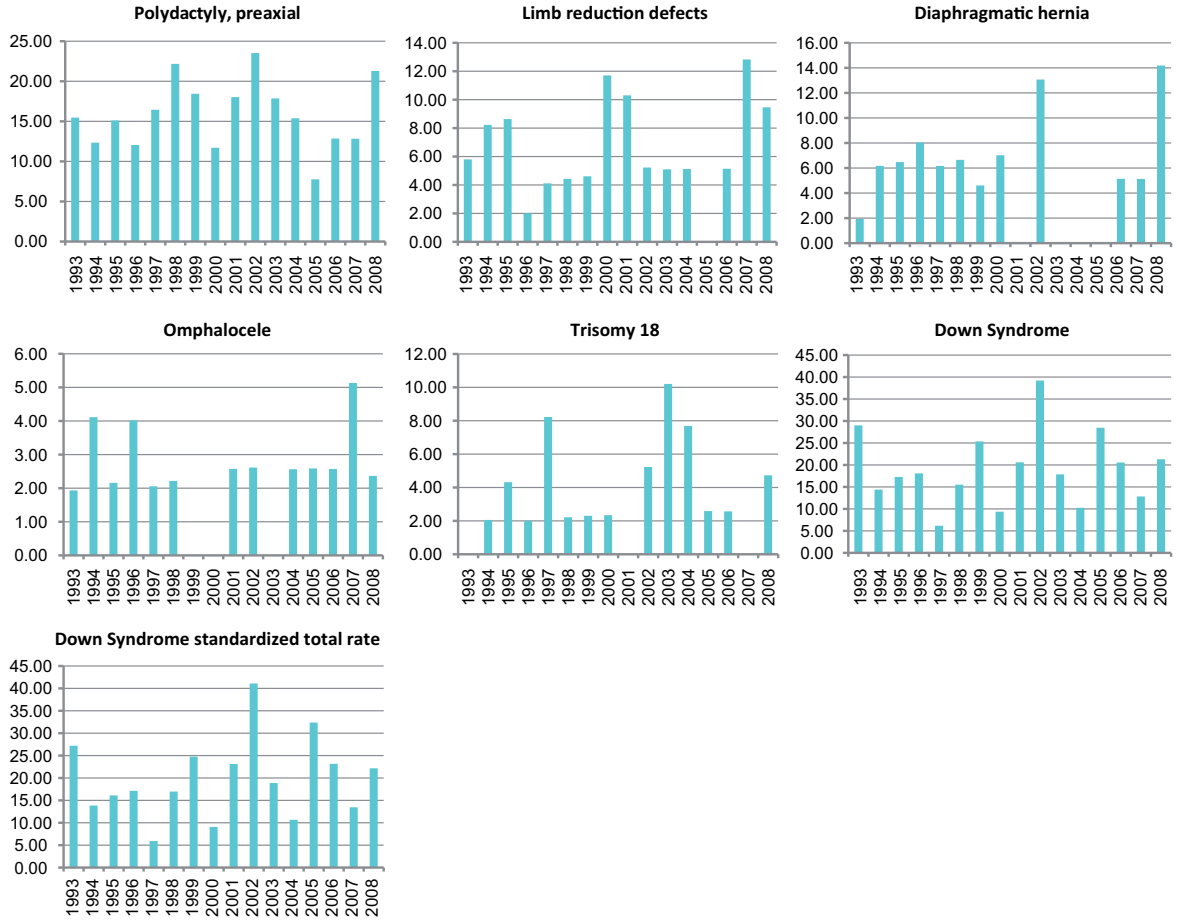
nr = not reported
* data include only 1 year

Malta: MCAR

Time trends 1993-2008 (Birth prevalence rates per 10,000)

Note: L+S rates

Malta: MCAR



Note: L+S rates

Mexico: RYVEMCE

Mexican Registry and Epidemiological Surveillance of External Congenital Malformations

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

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

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

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

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

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

Addresses and Staff:
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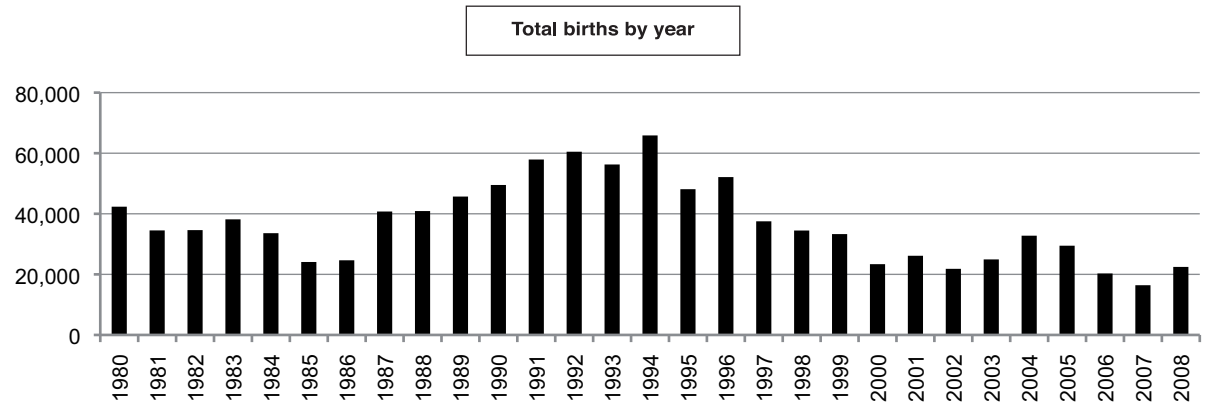
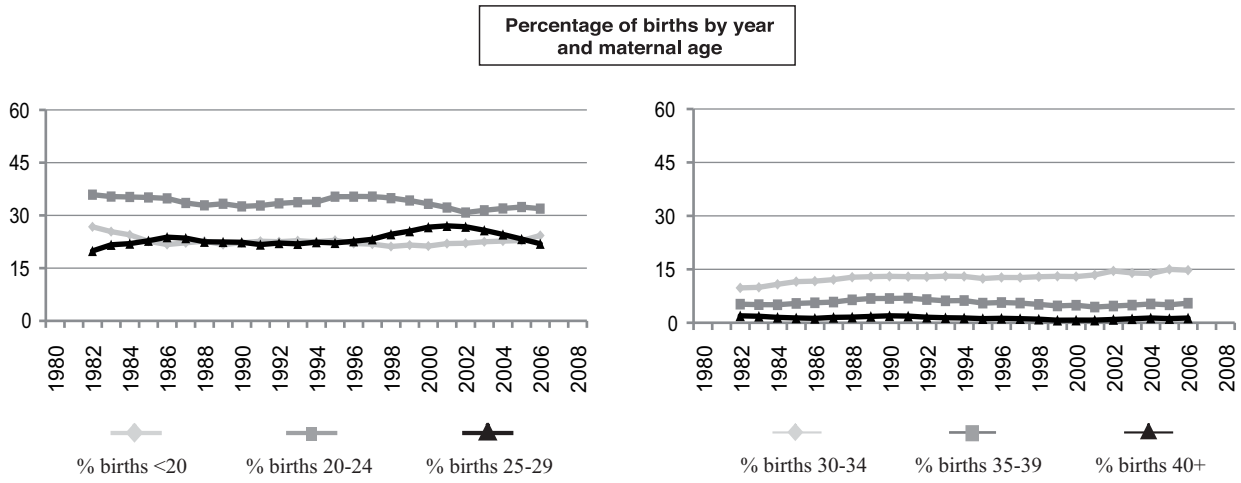
Vasco de Quiroga 15,Tlalpan, C.P.14000
Mexico DF, Mexico
Phone: 52-55-54870900 (ext 2514 and 2515)
Fax: 52-55-56556138
E-mail: osvaldo@servidor.unam.mx

Mexico: RYVEMCE





Mexico: RYVEMCE, 2008

Live births (LB)	21,855
Stillbirths (SB)	604
Total births	22,459
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	10		5.34
Spina bifida	8	1		4.01
Encephalocele	3	2		2.23
Microcephaly	7	0		3.12
Holoprosencephaly	1	1		0.89
Hydrocephaly	11	1		5.34
Anophthalmos	nr	nr		nr
Microphthalmos	nr	nr		nr
Unspecified Anophthalmos/Microphthalmos	4	2		2.67
Anotia	nr	nr		nr
Microtia	nr	nr		nr
Unspecified Anotia/Microtia	17	0		7.57
Transposition of great vessels	3	0		1.34
Tetralogy of Fallot	0	0		0.00
Hypoplastic left heart syndrome	1	0		0.45
Coarctation of aorta	2	0		0.89
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	3	1		1.78
Cleft lip with or without cleft palate	27	3		13.36
Oesophageal atresia/stenosis with or without fistula	1	1		0.89
Small intestine atresia/stenosis	1	1		0.89
Anorectal atresia/stenosis	9	2		4.90
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	5	0		2.23
Epispadias	1	0		0.45
Indeterminate sex	3	6		4.01
Renal agenesis	0	2		0.89
Cystic kidney	0	2		0.89
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	20	1		9.35
Total Limb reduction defects (include unspecified)	10	1		4.90
Transverse	7	0		3.12
Preaxial	1	0		0.45
Postaxial	1	0		0.45
Intercalary	1	0		0.45
Mixed	0	0		0.00
Unspecified	0	1		0.45
Diaphragmatic hernia	2	1		1.34
Omphalocele	6	0		2.67
Gastroschisis	10	1		4.90
Unspecified Omphalocele/Gastroschisis	nr	nr		nr
Prune belly sequence	1	0		0.45
Trisomy 13	1	1		0.89
Trisomy 18	2	0		0.89
Down syndrome, all ages (include age unknown)	24	0		10.69
<20	6	0		8.65
20-24	6	0		9.81
25-29	2	0		4.54
30-34	3	0		9.81
35-39	4	0		26.81
40-44	3	0		66.96
45+	0	0		0.00
unknown	0	0		---

nr = not reported

Mexico: RYVEMCE, Previous years rates 1980 - 2008

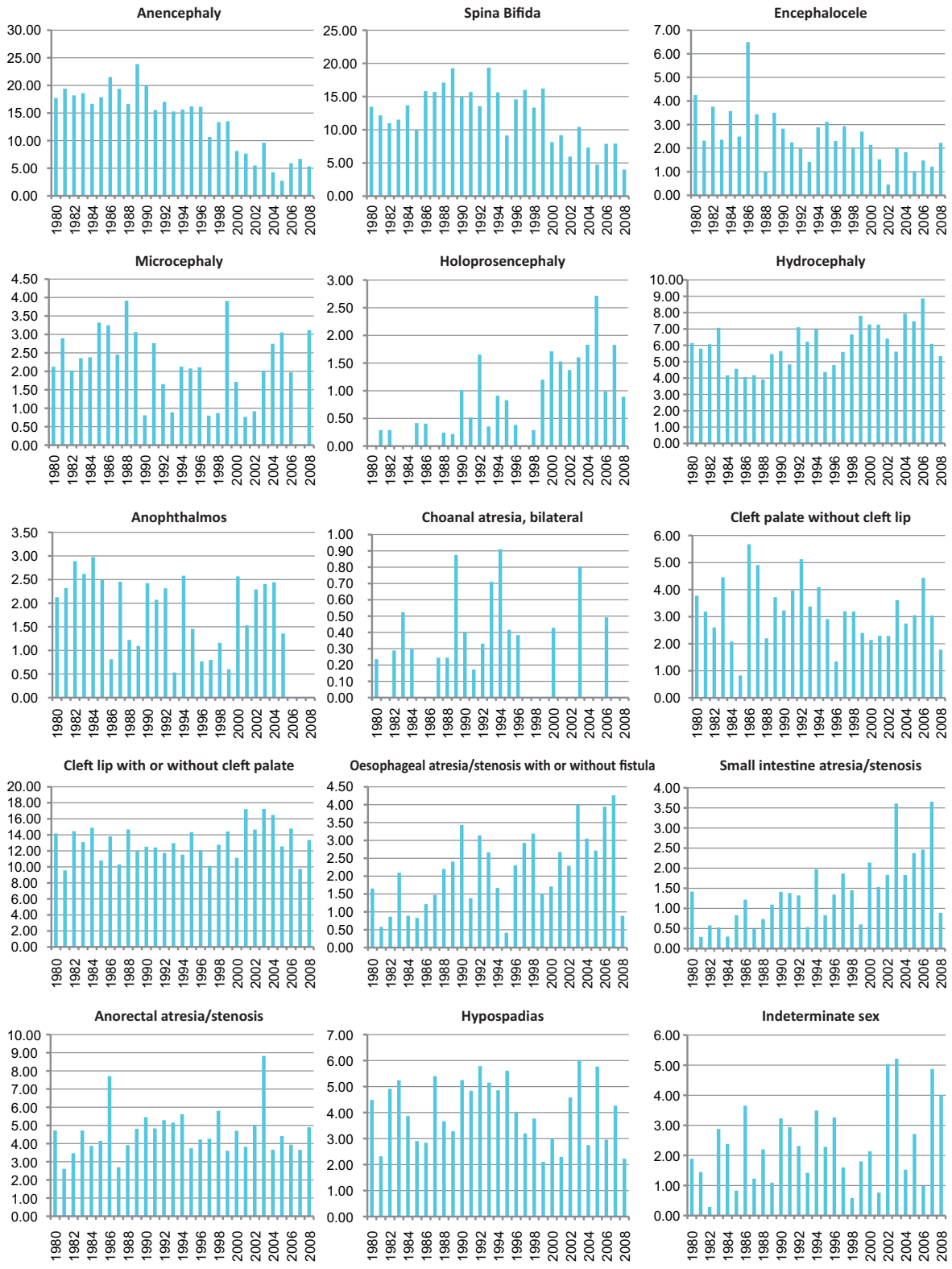
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**186,396**	**163,986**	**269,895**	**238,101**	**129,573**	**121,402**	
Anencephaly	18.45	18.23	18.04	14.74	9.26	4.70	
Spina bifida	12.10	14.82	16.45	13.82	10.50	6.26	
Encephalocele	3.21	3.17	2.33	2.69	1.85	1.57	
Microcephaly	2.34	3.05	1.82	1.72	2.01	2.39	
Holoprosencephaly	0.13	0.18	0.78	0.55	1.47	1.73	
Hydrocephaly	6.28	4.15	5.89	5.71	6.95	7.25	
Anophthalmos	2.47	2.01	1.70	1.47	1.78	1.93*	
Microphthalmos	nr	nr	nr	nr	nr	nr	
Unspecified Anophthalmos / Microphthalmos	nr	nr	nr	nr	nr	3.38*	
Anotia	nr	nr	nr	nr	nr	nr	
Microtia	nr	nr	nr	nr	nr	nr	
Unspecified Anotia / Microtia	6.75	5.98	7.00	6.13	8.49	8.81	
Transposition of great vessels	0.07	0.12	0.15	0.08	0.39	0.66	
Tetralogy of Fallot	0.00	0.00	0.15	0.21	0.23	0.16	
Hypoplastic left heart syndrome	0.00	0.00	0.04	0.00	0.15	0.25	
Coarctation of aorta	0.07	0.00	0.04	0.13	0.00	0.25	
Choanal atresia, bilateral	0.27	0.18	0.48	0.42	0.23	0.08	
Cleft palate without cleft lip	3.54	3.17	3.93	2.98	2.55	2.97	
Cleft lip with or without cleft palate	12.90	12.93	12.34	12.18	14.97	13.76	
Oesophageal atresia / stenosis with or without fistula	1.34	1.40	2.59	1.97	2.39	2.88	
Small intestine atresia / stenosis	0.74	0.67	1.15	1.51	1.85	2.14	
Anorectal atresia / stenosis	3.94	4.21	5.11	4.75	5.09	4.12	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	
Hypospadias	4.28	3.90	4.93	4.41	3.47	3.62	
Epispadias	nr	nr	nr	nr	nr	0.16	
Indeterminate sex	1.67	2.01	2.22	2.48	2.86	2.64	
Renal agenesis	0.33	0.37	0.59	0.55	0.54	0.99	
Cystic kidney	0.20	0.55	0.70	0.88	2.01	0.91	
Bladder exstrophy	0.33	0.55	0.52	0.34	0.39	0.08	
Polydactyly, preaxial	11.76	13.11	13.08	11.84	14.43	9.39	
Total Limb reduction defects (include unspecified)	6.55	6.10	6.30	5.38	6.25	6.34	
Transverse	nr	nr	nr	nr	3.53*	3.38	
Preaxial	nr	nr	nr	nr	1.25*	0.82	
Postaxial	nr	nr	nr	nr	0.31*	0.49	
Intercalary	nr	nr	nr	nr	0.42*	0.41	
Mixed	nr	nr	nr	nr	0.93*	0.82	
Unspecified	6.55	6.10	6.30	5.38	0.00	0.41	
Diaphragmatic hernia	0.53	0.67	1.04	1.09	1.16	1.15	
Omphalocele	1.67	1.46	1.45	1.93	2.16	1.89	
Gastroschisis	0.80	1.16	1.63	2.73	4.55	5.19	
Unspecified Omphalocele / Gastroschisis	nr	nr	nr	nr	nr	0.00*	
Prune belly sequence	1.34	0.91	1.30	0.55	1.00	0.25	
Trisomy 13	0.40	0.24	0.19	0.13	0.39	0.74	
Trisomy 18	0.67	0.55	0.41	0.25	0.23	0.66	
Down syndrome, all ages (include age unknown)	12.70	13.29	13.93	12.73	11.58	11.37	
<20	5.76	8.57	10.54	7.36	4.88	9.47	
20-24	7.05	5.24	8.36	5.83	5.94	7.29	
25-29	7.86	6.92	12.57	8.76	5.46	7.08	
30-34	21.83	17.36	13.07	12.32	15.68	8.44	
35-39	44.78	52.38	32.32	50.65	63.45	39.73	
40-44	112.36	207.78	89.94	209.21	285.71	119.42	
45+	137.46	86.21*	207.25	123.08*	nr	123.46*	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

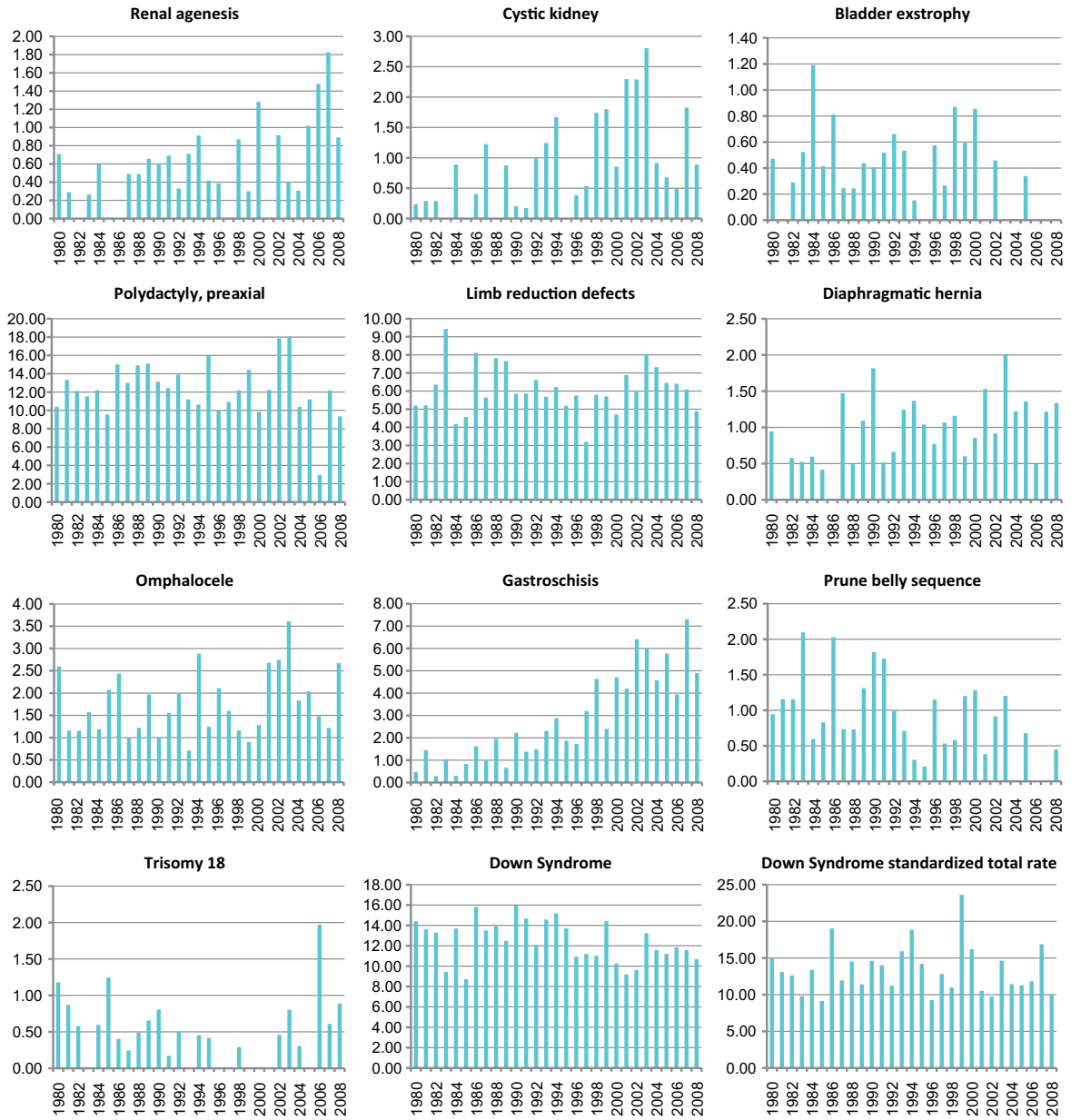
Mexico: RYVEMCE

Time trends 1980-2008 (Birth prevalence rates per 10,000)



Note: L+S rates

Mexico: RYVEMCE



Note: L+S rates

New Zealand
New Zealand Birth Defects Registry

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

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

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.

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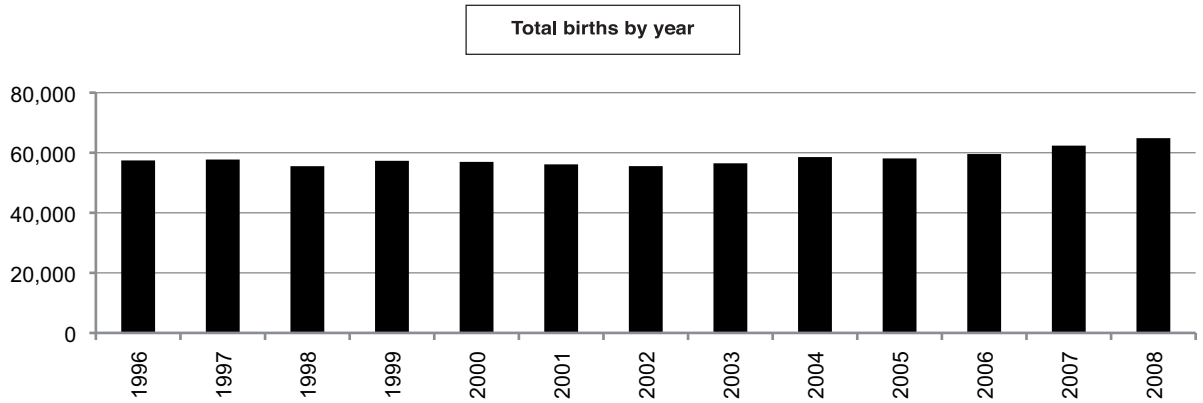
New Zealand


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

New Zealand, 2008

Live births (LB)	64,343
Stillbirths (SB)	507
Total births	64,850
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	nr	nr	0.15
Spina bifida	19	nr	nr	2.93
Encephalocele	5	nr	nr	0.77
Microcephaly	22	nr	nr	3.39
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	19	nr	nr	2.93
Anophthalmos	1	nr	nr	0.15
Microphthalmos	0	nr	nr	0.00
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	32	nr	nr	4.93
Tetralogy of Fallot	29	nr	nr	4.47
Hypoplastic left heart syndrome	12	nr	nr	1.85
Coarctation of aorta	15	nr	nr	2.31
Choanal atresia, bilateral	6	nr	nr	0.93
Cleft palate without cleft lip	44	nr	nr	6.78
Cleft lip with or without cleft palate	44	nr	nr	6.78
Oesophageal atresia/stenosis with or without fistula	12	nr	nr	1.85
Small intestine atresia/stenosis	18	nr	nr	2.78
Anorectal atresia/stenosis	14	nr	nr	2.16
Undescended testis (36 weeks of gestation or later)	412	nr	nr	63.53
Hypospadias	153	nr	nr	23.59
Epispadias	nr	nr	nr	nr
Indeterminate sex	8	nr	nr	1.23
Renal agenesis	19	nr	nr	2.93
Cystic kidney	50	nr	nr	7.71
Bladder exstrophy	0	nr	nr	0.00
Polydactyly, preaxial	80	nr	nr	12.34
Total Limb reduction defects (include unspecified)	nr	nr	nr	nr
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	20	nr	nr	3.08
Omphalocele	nr	nr	nr	nr
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	1	nr	nr	0.15
Trisomy 18	7	nr	nr	1.08
Down syndrome, all ages (include age unknown)	61	nr	nr	9.41
<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 - 2008

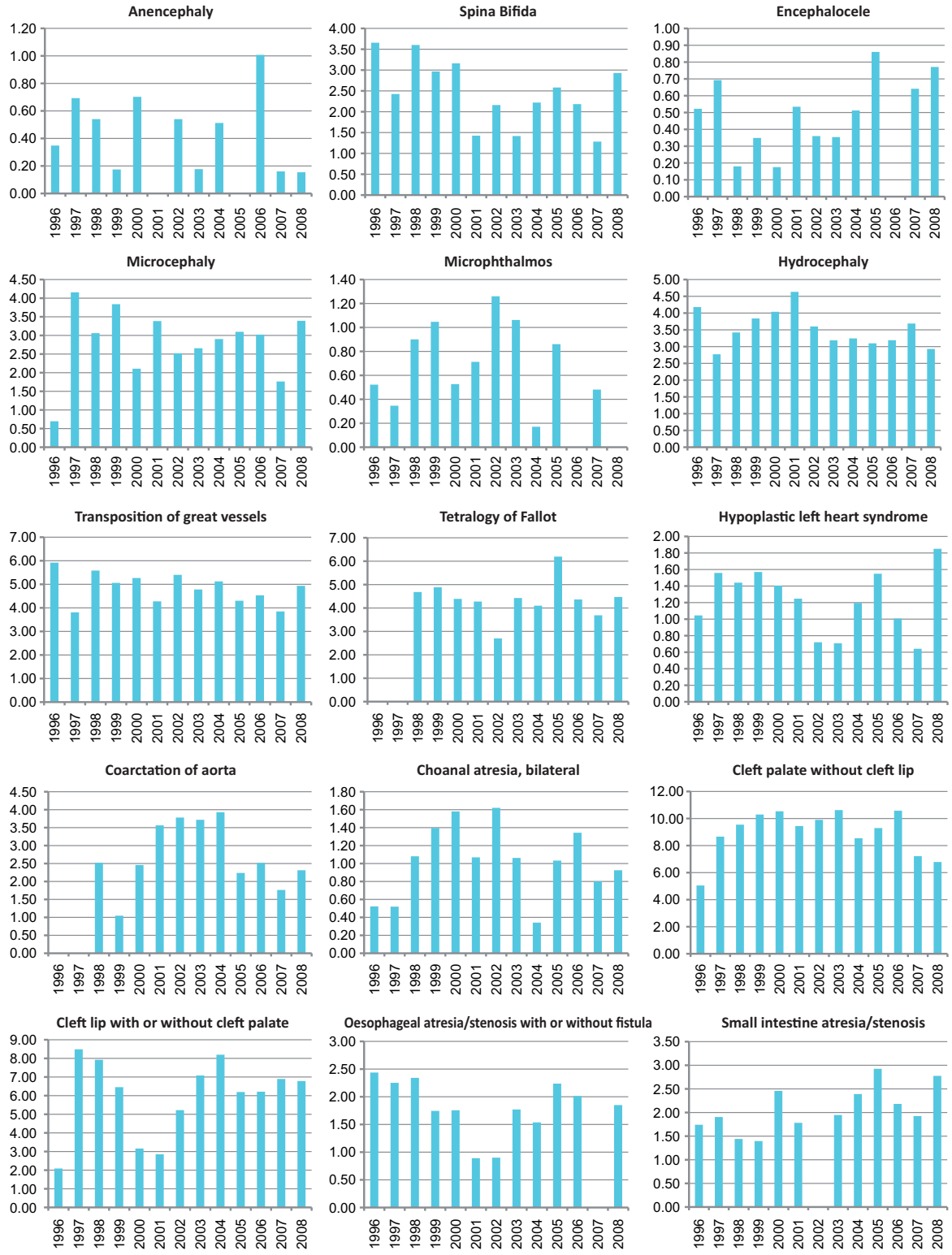
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**194,693**	**263,305**	**296,449**	**285,914**	**282,403**	**303,436**	
Anencephaly	5.86	2.92	1.05	0.52	0.32	0.36	
Spina bifida	11.30	7.79	3.88	3.57	2.23	2.24	
Encephalocele	0.79	0.68	nr	0.35*	0.35	0.56	
Microcephaly	nr	nr	nr	2.64*	2.90	2.83	
Holoprosencephaly	nr	nr	nr	nr	nr	nr	
Hydrocephaly	4.67	3.46	2.63	3.32	3.86	3.23	
Anophthalmos	nr	nr	nr	0.00*	0.04	0.16*	
Microphthalmos	nr	nr	nr	0.59*	0.92	0.37*	
Unspecified Anophthalmos / Microphthalmos	nr	nr	nr	0.00*	0.00	0.17*	
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	5.10*	4.96	4.55	
Tetralogy of Fallot	nr	nr	nr	4.68*	4.14	4.55	
Hypoplastic left heart syndrome	nr	0.82*	nr	1.49*	1.13	1.25	
Coarctation of aorta	nr	nr	nr	2.52*	2.90	2.54	
Choanal atresia, bilateral	nr	nr	nr	0.70*	1.35	0.89	
Cleft palate without cleft lip	6.11	7.60	5.46	6.54	10.16	8.44	
Cleft lip with or without cleft palate	8.68	8.70	5.16	4.72	4.96	6.85	
Oesophageal atresia / stenosis with or without fistula	1.75	1.94	2.02	2.45	1.42	1.91*	
Small intestine atresia / stenosis	nr	nr	nr	1.70*	1.90*	2.44	
Anorectal atresia / stenosis	2.57	2.43	2.53	2.62	2.41	2.34	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	58.10*	77.30	62.75	
Hypospadias	12.89	13.79	11.77	18.63*	29.60	27.52	
Epispadias	nr	nr	nr	nr	nr	nr	
Indeterminate sex	nr	nr	nr	0.53*	0.57	0.89	
Renal agenesis	nr	0.34	nr	3.80*	3.01	3.00	
Cystic kidney	nr	nr	nr	6.21*	5.77	5.60	
Bladder exstrophy	nr	nr	nr	0.43*	0.32	0.10	
Polydactyly, preaxial	nr	nr	nr	5.99*	10.47*	14.93	
Total Limb reduction defects (include unspecified)	4.01	3.04	2.73	2.27	2.76	2.31*	
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	4.01	3.04	2.73	2.27	2.76	2.01*	
Diaphragmatic hernia	0.99	1.60	nr	2.34*	2.62	2.34*	
Omphalocele	2.49	1.90	2.06	2.44*	nr	4.17*	
Gastroschisis	0.00	0.65	nr	nr	nr	nr	
Unspecified Omphalocele / Gastroschisis	0.00	0.30	nr	nr	nr	5.01*	
Prune belly sequence	nr	nr	nr	nr	nr	nr	
Trisomy 13	nr	nr	nr	0.59*	0.28	0.56	
Trisomy 18	nr	nr	nr	0.94*	1.27	1.09	
Down syndrome, all ages (include age unknown)	8.22	9.68*	9.49*	9.90	12.07	10.15	
<20	4.20	7.29*	nr	nr	nr	nr	
20-24	4.64	3.76*	nr	nr	nr	nr	
25-29	7.99	9.04*	nr	nr	nr	nr	
30-34	10.00	9.11*	nr	nr	nr	nr	
35-39	29.63	34.94*	nr	nr	nr	nr	
40-44	60.98	221.38*	nr	nr	nr	nr	
45+	82.64	219.78*	nr	nr	nr	nr	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

New Zealand

Time trends 1996-2008 (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. 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 16 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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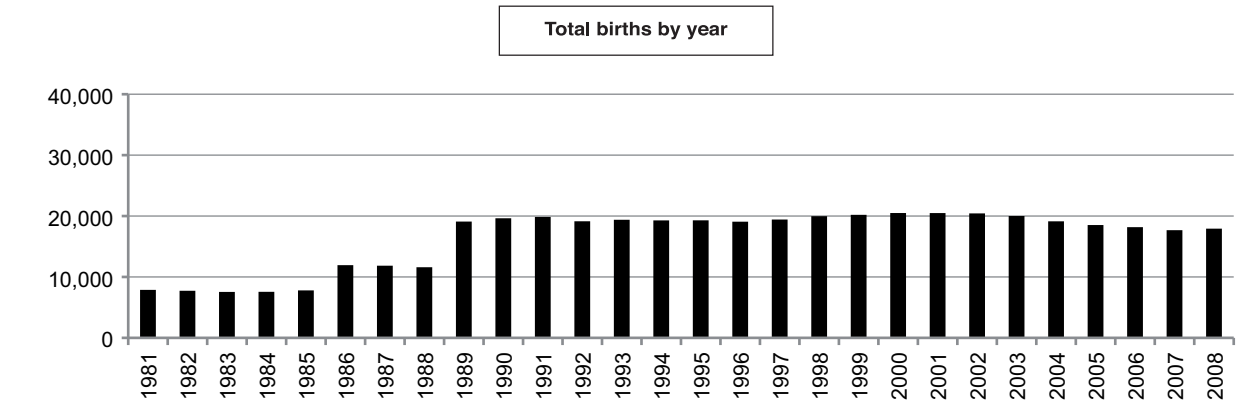
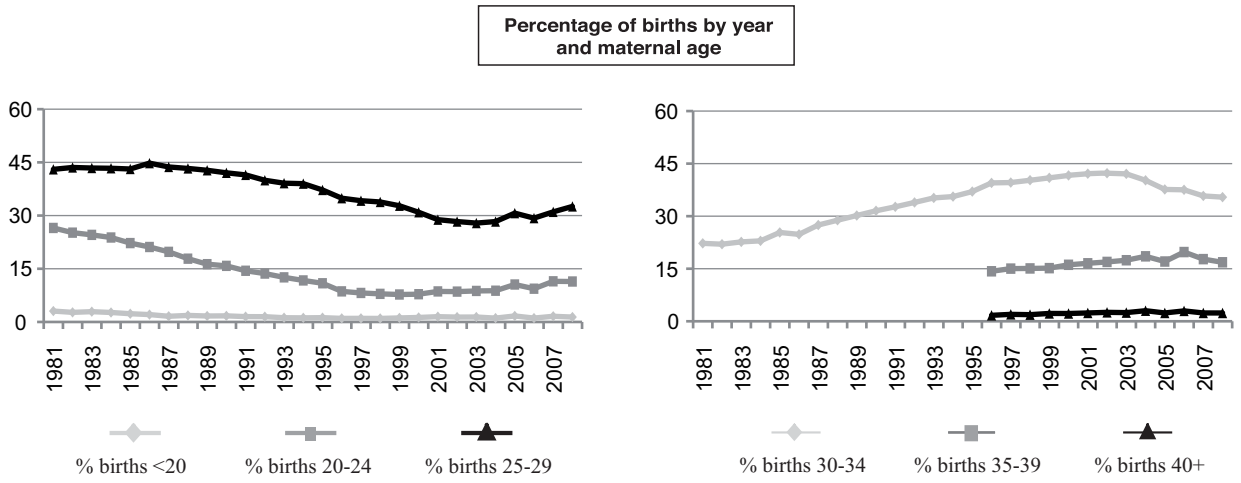
Northern Netherlands





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	6	42.9	Cystic kidney	7	38.9
Spina bifida	8	36.4	Limb reduction defects	4	20.0
Encephalocele	3	33.3	Diaphragmatic hernia	9	52.9
Holoprosencephaly	2	100.0	Omphalocele	6	75.0
Hydrocephaly	14	38.9	Gastroschisis	2	50.0
Hypoplastic left heart syndrome	9	42.9	Trisomy 13	8	80.0
Cleft palate without cleft lip	1	4.2	Trisomy 18	26	74.3
Cleft lip with or without cleft palate	3	5.5	Down syndrome	35	40.7
Renal agenesis	7	35.0			

Total ToPs with births defects = 163 (Ratio ToPs/Births: 0.03 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Northern Netherlands, 2008

Live births (LB)	17,848
Stillbirths (SB)	81
Total births	17,929
Number of terminations of pregnancy (ToP) for birth defects	72

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	2	1.12
Spina bifida	3	0	5	4.46
Encephalocele	0	0	1	0.56
Microcephaly	4	0	0	2.23
Holoprosencephaly	0	0	2	1.12
Hydrocephaly	1	0	8	5.02
Anophthalmos	0	0	0	0.00
Microphthalmos	5	0	0	2.79
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.56
Microtia	1	0	0	0.56
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	5	0	2	3.90
Tetralogy of Fallot	3	0	1	2.23
Hypoplastic left heart syndrome	2	0	4	3.35
Coarctation of aorta	7	1	0	4.46
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	11	0	0	6.14
Cleft lip with or without cleft palate	20	1	0	11.71
Oesophageal atresia/stenosis with or without fistula	3	0	0	1.67
Small intestine atresia/stenosis	5	0	0	2.79
Anorectal atresia/stenosis	3	0	2	2.79
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	35	0	0	19.52
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	2	1.67
Renal agenesis	6	0	5	6.14
Cystic kidney	5	0	5	5.58
Bladder exstrophy	0	0	1	0.56
Polydactyly, preaxial	1	0	0	0.56
Total Limb reduction defects (include unspecified)	7	0	2	5.02
Transverse	6	0	2	4.46
Preaxial	0	0	0	0.00
Postaxial	2	0	0	1.12
Intercalary	0	0	0	0.00
Mixed	2	0	0	1.12
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	1	0	2	1.67
Omphalocele	0	0	2	1.12
Gastroschisis	2	0	2	2.23
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	1	0	1.12
Trisomy 18	2	0	11	7.25
Down syndrome, all ages (include age unknown)	12	1	15	15.62
<20	0	0	0	0.00
20-24	2	0	0	9.78
25-29	1	0	1	3.42
30-34	5	0	6	17.32
35-39	3	1	6	33.13
40-44	1	0	2	71.60
45+	0	0	0	0.00
unknown				---

nr = not reported

Northern Netherlands, Previous years rates 1981 - 2008

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

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births		**23,150**	**50,729**	**97,108**	**97,054**	**101,617**	**91,436**
Anencephaly		6.91	5.91	2.37	3.30	2.76	1.97
Spina bifida		5.62	6.11	7.83	5.46	4.43	4.70
Encephalocele		1.73	1.38	1.13	0.72	0.98	1.20
Microcephaly		4.75	4.34	3.71	4.12	4.03	2.73
Holoprosencephaly		1.73	1.58	0.51	0.82	1.48	0.66
Hydrocephaly		3.46	4.14	3.30	3.40	4.23	5.14
Anophthalmos		0.00	0.20	0.41	0.21	0.39	2.95
Microphthalmos		2.16	1.18	1.96	1.96	0.89	1.97
Unspecified Anophthalmos / Microphthalmos		nr	nr	nr	nr	nr	1.65*
Anotia		3.02	1.18	0.82	1.03	1.08	1.53
Microtia		0.86	0.59	1.13	0.72	0.89	0.44
Unspecified Anotia / Microtia		nr	nr	nr	nr	nr	24.76*
Transposition of great vessels		2.59	3.35	3.71	5.46	3.84	3.94
Tetralogy of Fallot		6.05	2.76	3.81	2.58	4.13	2.41
Hypoplastic left heart syndrome		3.46	2.17	2.37	2.27	2.46	3.28
Coarctation of aorta		6.91	4.93	5.35	6.08	4.72	5.47
Choanal atresia, bilateral		1.73	0.79	1.24	0.93	1.08	0.55
Cleft palate without cleft lip		8.21	6.11	7.31	6.49	9.55	4.92
Cleft lip with or without cleft palate		15.98	15.77	14.11	15.97	14.37	11.48
Oesophageal atresia / stenosis with or without fistula		3.02	2.96	2.47	4.02	3.84	2.95
Small intestine atresia / stenosis		2.59	3.35	2.37	2.58	2.16	1.53
Anorectal atresia / stenosis		2.16	3.75	2.78	3.50	4.13	2.41
Undescended testis (36 weeks of gestation or later)		0.00	0.39	0.00	0.00	0.00	0.14*
Hypospadias		19.44	9.07	10.09	13.29	17.02	18.48
Epispadias		0.00	0.79	0.41	0.62	0.49	0.27*
Indeterminate sex		0.00	0.39	0.21	0.52	0.39	0.87
Renal agenesis		2.59	5.52	3.91	4.53	5.51	3.39
Cystic kidney		2.16	4.34	5.05	5.15	3.54	4.48
Bladder exstrophy		0.00	0.20	0.31	0.10	0.30	0.27
Polydactyly, preaxial		2.59	1.58	1.85	2.06	1.97	0.77
Total Limb reduction defects (include unspecified)		9.50	5.72	6.69	6.08	6.30	5.03
Transverse		6.48	2.76	3.71	3.50	3.84	4.59
Preaxial		2.16	0.59	1.03	0.62	0.89	4.05
Postaxial		0.86	0.99	1.34	1.34	1.48	1.42
Intercalary		0.43	0.00	0.31	0.10	0.10	0.22
Mixed		0.86	0.00	0.51	0.10	1.28	2.19
Unspecified		nr	1.38	nr	0.41	nr	4.95*
Diaphragmatic hernia		1.73	3.35	2.16	3.92	2.07	2.52
Omphalocele		1.30	1.97	3.09	2.68	2.07	1.64
Gastroschisis		1.30	0.79	0.51	0.62	1.08	0.87
Unspecified Omphalocele / Gastroschisis		nr	nr	nr	nr	nr	nr
Prune belly sequence		0.43	0.20	0.51	0.31	0.39	0.11
Trisomy 13		0.43	0.99	1.44	1.03	1.18	1.64
Trisomy 18		2.59	2.37	1.85	3.19	3.94	6.67
Down syndrome, all ages (include age unknown)		9.94	15.97	13.59	15.35	15.75	16.08
<20		0.00	0.00	0.00	0.00	0.00	0.00
20-24		10.19	5.73	9.20	6.54	4.74	6.38
25-29		3.99	13.53	8.02	6.04	9.26	7.94
30-34		9.69	12.81	13.22	13.14	9.41	14.06
35-39		42.89	58.25	30.46	40.87	33.53	31.04
40-44		nr	nr	nr	113.64*	124.57	81.44
45+		nr	nr	nr	0.00*	243.90	153.85
unknown		---	---	---	---	---	---

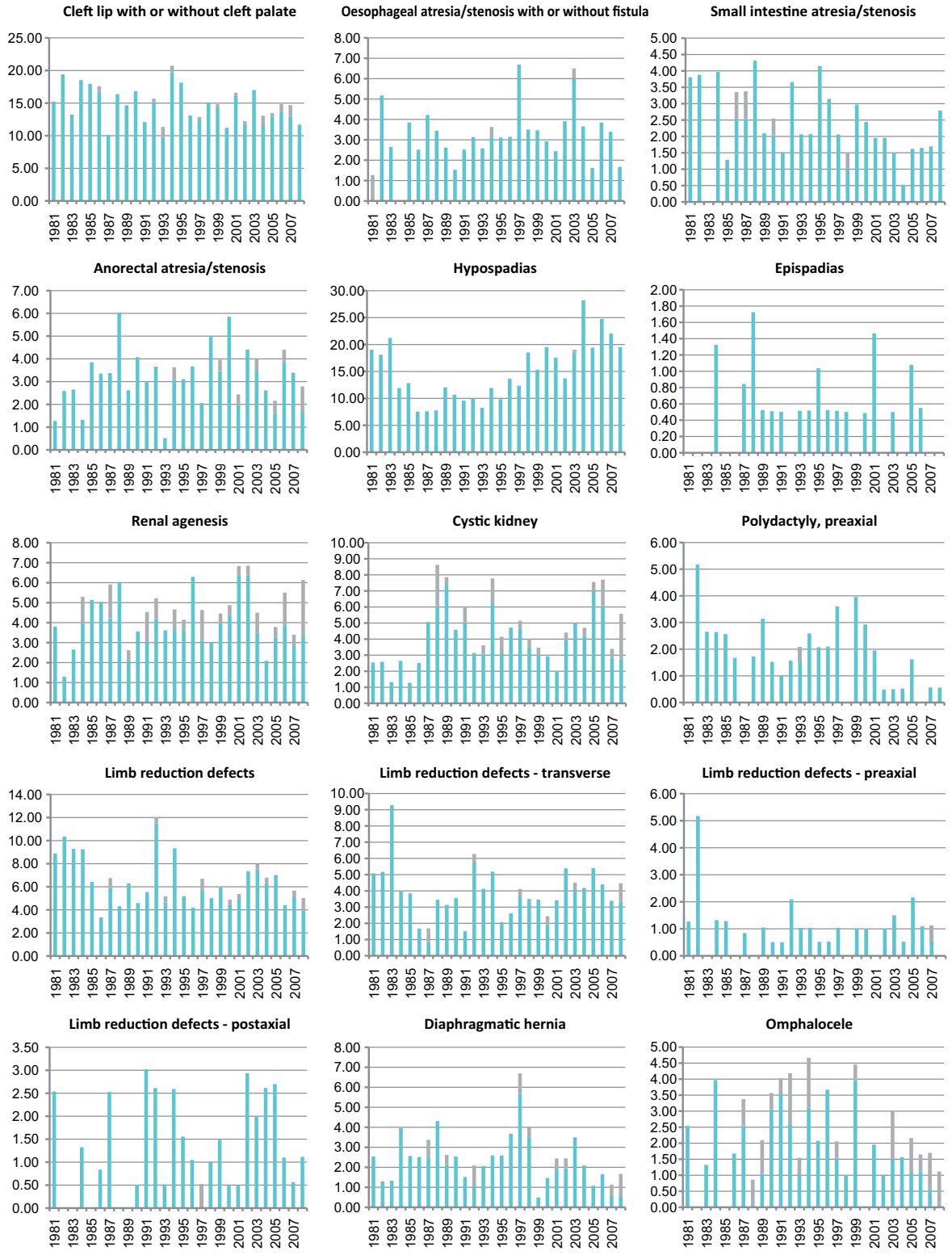
nr = not reported
* data include less than 5 years

Northern Netherlands

Time trends 1981-2008 (Birth prevalence rates per 10,000)

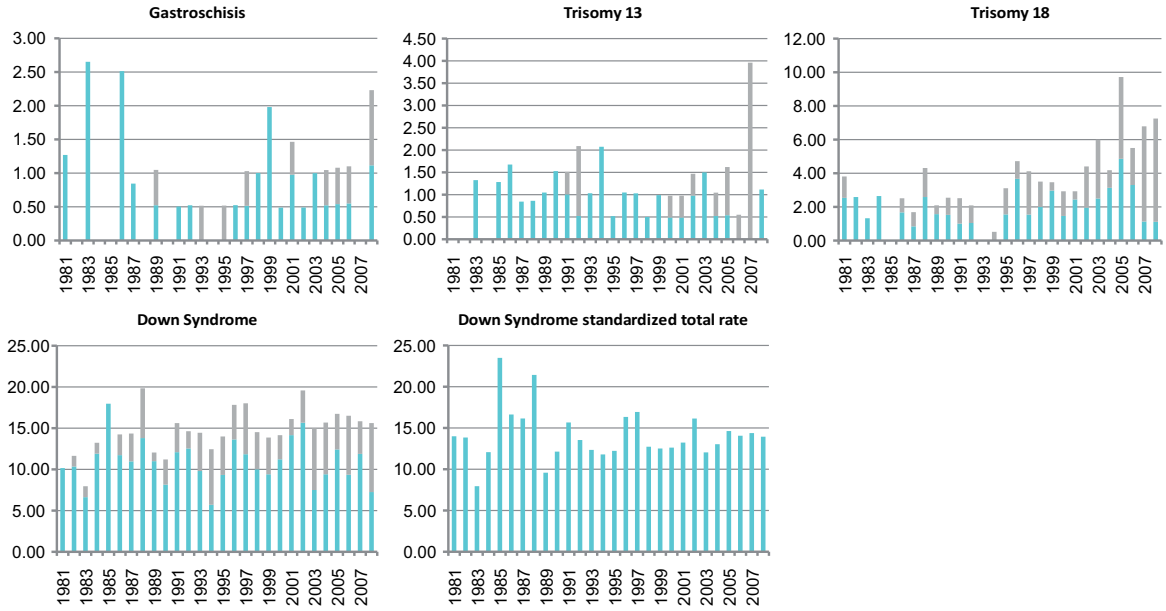
Note: L+S rates, ToP rates

Northern Netherlands



Note: L+S rates, ToP rates

Northern Netherlands



Note: L+S rates, ToP rates

Norway: MBRN
Medical Birth Registry of Norway

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

Size and coverage:
The Programme covers all births in Norway, approximately 60,000 annual births.
1999-2000: Stillbirths of 16 weeks or more gestation are included. Abortions from 12 weeks are included.
Starting from 2001: Stillbirths and abortions from 12 weeks or more are included.

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:
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Medical Birth Registry of Norway
Norwegian Institute of Public Health
Kalfarveien 31
N-5018 Bergen, Norway
Phone: 47- 53 20 4002
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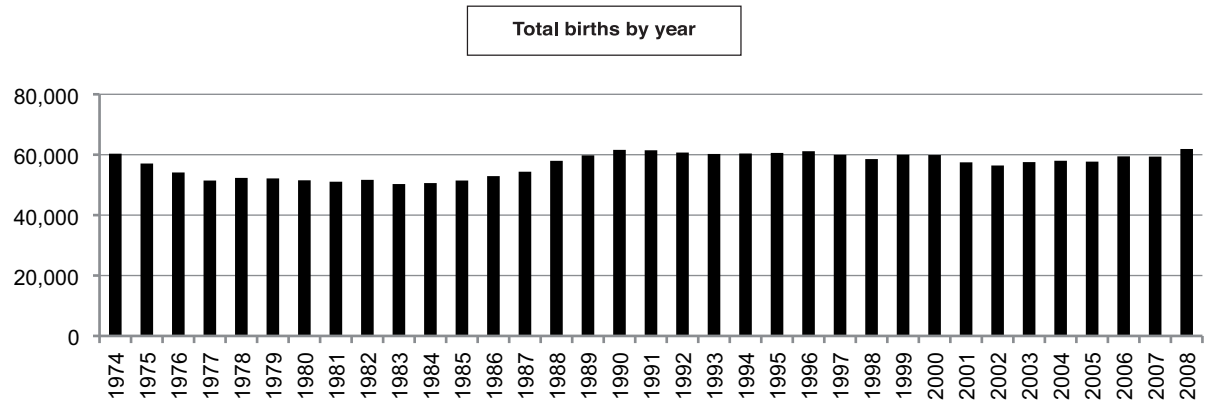
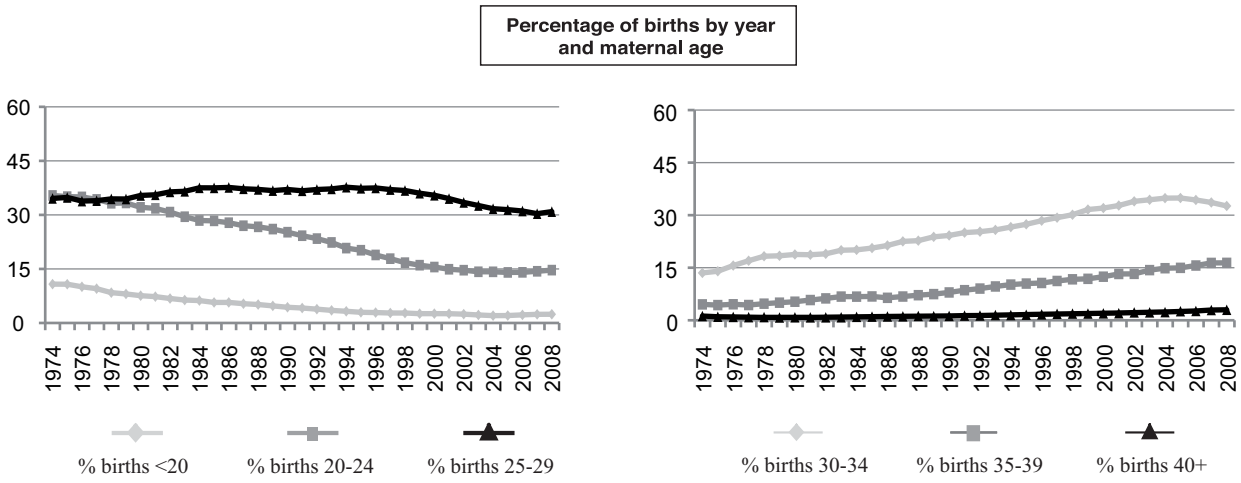
E-mail: vollset@uib.no

Norway: MBRN





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	56	80.0	Cystic kidney	41	39.8
Spina bifida	43	51.2	Limb reduction defects	27	30.7
Encephalocele	5	41.7	Diaphragmatic hernia	11	26.2
Holoprosencephaly	21	87.5	Omphalocele	20	46.5
Hydrocephaly	33	35.9	Gastroschisis	11	19.0
Hypoplastic left heart syndrome	25	41.0	Trisomy 13	29	72.5
Cleft palate without cleft lip	5	4.1	Trisomy 18	44	60.3
Cleft lip with or without cleft palate	23	9.3	Down syndrome	44	15.5
Renal agenesis	14	51.9			

Total ToPs with births defects = 754 (Ratio ToPs/Births: 4.19 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Norway: MBRN, 2008

Live births (LB)	61,233
Stillbirths (SB)	401
Total births	61,894
Number of terminations of pregnancy (ToP) for birth defects	260

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	1	20	4.04
Spina bifida	10	0	22	5.17
Encephalocele	1	0	2	0.48
Microcephaly	2	0	2	0.65
Holoprosencephaly	0	0	10	1.62
Hydrocephaly	11	0	8	3.07
Anophthalmos	1	0	1	0.32
Microphthalmos	2	0	1	0.48
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	1	0.32
Microtia	5	0	1	0.97
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	25	0	4	4.69
Tetralogy of Fallot	14	0	3	2.75
Hypoplastic left heart syndrome	13	0	13	4.20
Coarctation of aorta	16	0	5	3.39
Choanal atresia, bilateral	6	0	2	1.29
Cleft palate without cleft lip	28	0	3	5.01
Cleft lip with or without cleft palate	66	2	11	12.76
Oesophageal atresia/stenosis with or without fistula	18	0	3	3.39
Small intestine atresia/stenosis	6	0	0	0.97
Anorectal atresia/stenosis	14	0	7	3.39
Undescended testis (36 weeks of gestation or later)	165	0	0	26.66
Hypospadias	87	0	0	14.06
Epispadias	1	0	0	0.16
Indeterminate sex	3	0	0	0.48
Renal agenesis	2	0	6	1.29
Cystic kidney	19	0	13	5.17
Bladder exstrophy	2	0	0	0.32
Polydactyly, preaxial	42	1	5	7.76
Total Limb reduction defects (include unspecified)	13	1	10	3.88
Transverse	8	0	2	1.62
Preaxial	1	0	2	0.48
Postaxial	1	0	0	0.16
Intercalary	0	0	0	0.00
Mixed	5	1	7	2.10
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	11	0	4	2.42
Omphalocele	6	0	12	2.91
Gastroschisis	15	2	6	3.72
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	7	1	11	3.07
Trisomy 13	2	0	17	3.07
Trisomy 18	10	2	21	5.33
Down syndrome, all ages (include age unknown)	68	0	nr	6.46
<20	nr	nr	nr	nr
20-24	5	nr	1	40.05
25-29	15	nr	3	19.83
30-34	8	nr	6	7.32
35-39	28	nr	16	21.79
40-44	9	nr	16	24.65
45+	3	nr	1	22.51
unknown				---

nr = not reported

Norway: MBRN, Previous years rates 1974 - 2008

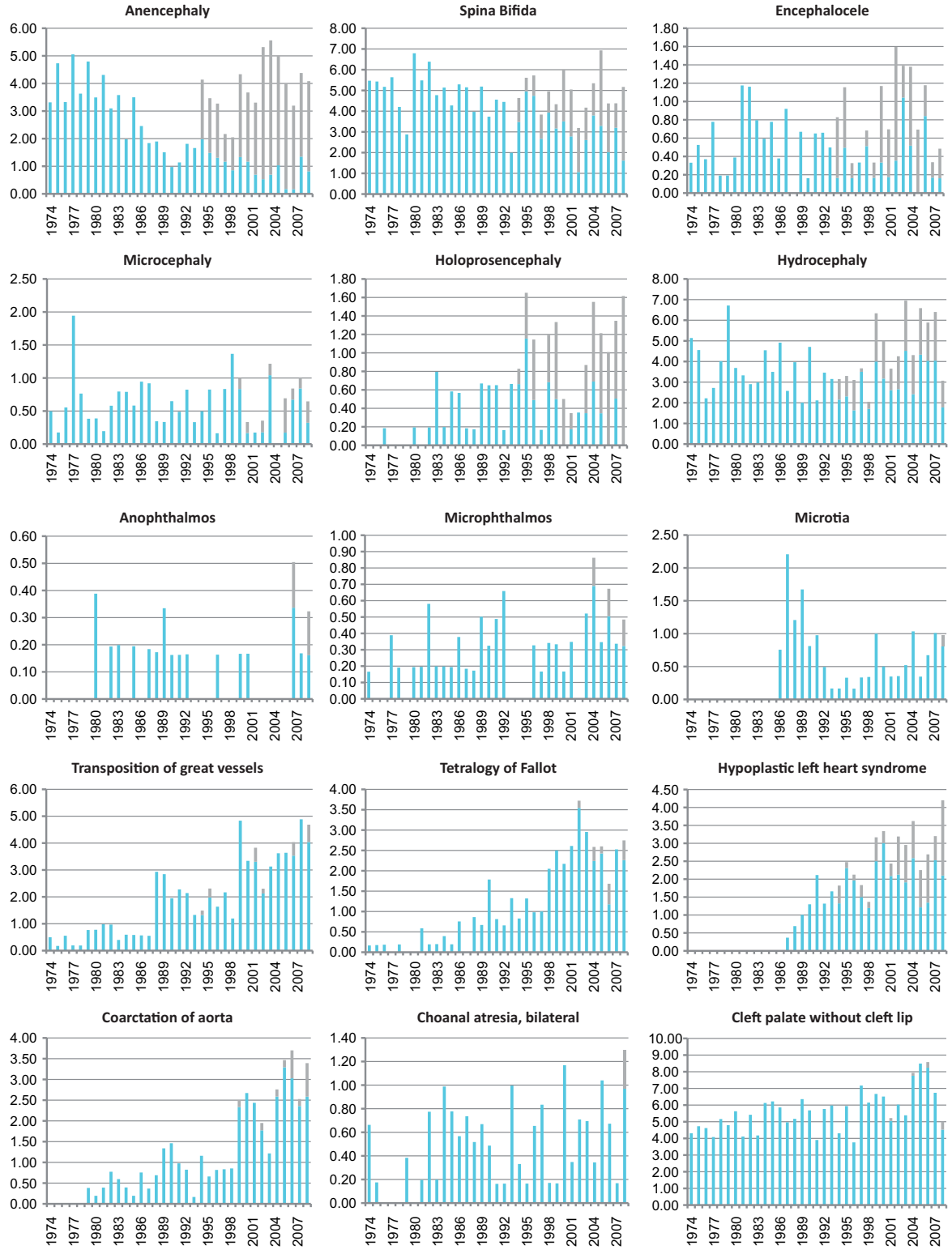
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**275,304**	**256,698**	**267,316**	**303,808**	**300,662**	**291,333**	**295,756**
Anencephaly	4.00	3.86	2.32	1.42	3.03	4.43	4.13
Spina bifida	5.19	5.26	4.75	3.98	4.96	4.57	5.23
Encephalocele	0.44	0.74	0.52	0.53	0.67	1.03	0.8
Microcephaly	0.76	0.47	0.71	0.53	0.73	0.62	0.64
Holoprosencephaly	0.04	0.23	0.34	0.56	1.00	0.69	1.35
Hydrocephaly	3.78	3.93	3.89	3.09	3.06	5.25	5.23
Anophthalmos	0.00	0.16	0.11	0.16	0.03	0.07	0.20
Microphthalmos	0.15	0.23	0.22	0.39	0.17	0.27	0.54
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00*
Anotia	0.15	0.16	0.26	0.07	0.27	0.24	0.17
Microtia	nr	nr	1.39*	0.82	0.27	0.55	0.81
Unspecified Anotia / Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.33	0.78	1.08	2.11	1.76	3.50	4.18
Tetralogy of Fallot	0.15	0.19	0.45	1.05	1.23	2.78	2.43
Hypoplastic left heart syndrome	nr	nr	0.53*	1.48	1.93	3.02	3.20
Coarctation of aorta	nr	0.47	0.49	0.95	0.86	2.16	3.17
Choanal atresia, bilateral	0.18	0.31	0.71	0.49	0.43	0.62	0.71
Cleft palate without cleft lip	4.58	4.83	5.65	5.53	5.45	5.97	7.32
Cleft lip with or without cleft palate	14.06	14.53	13.88	13.07	13.87	12.94	13.12
Oesophageal atresia / stenosis with or without fistula	2.18	1.68	1.95	2.57	1.70	2.85	2.70
Small intestine atresia / stenosis	0.87	1.17	0.90	1.58	1.63	0.89	0.98
Anorectal atresia / stenosis	1.60	1.79	2.13	2.76	1.86	2.61	3.20
Undescended testis (36 weeks of gestation or later)	18.31	14.69	15.08	18.30	15.07	26.05	27.09
Hypospadias	12.39	13.48	16.68	15.47	14.47	16.68	14.78
Epispadias	0.25	0.31	0.45	0.23	0.33	0.27	0.13
Indeterminate sex	2.11	3.78	3.67	4.74	8.88	0.51	0.37
Renal agenesis	0.15	0.62	1.01	1.58	1.53	1.13	1.32
Cystic kidney	0.51	0.70	1.50	2.40	2.53	5.01	5.16
Bladder exstrophy	0.22	0.39	0.41	0.23	0.37	0.31	0.27
Polydactyly, preaxial	nr	nr	nr	nr	nr	8.17	9.45
Total Limb reduction defects (include unspecified)	7.92	7.48	7.89	6.45	6.85	4.15	4.62
Transverse	nr	nr	nr	3.42	3.43	2.03	2.19
Preaxial	nr	nr	nr	0.79	0.33	0.51	0.47
Postaxial	nr	nr	nr	0.69	0.43	0.10	0.10
Intercalary	nr	nr	nr	0.26	0.57	0.10	0.13
Mixed	nr	nr	nr	0.49	0.90	1.65	1.99
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	1.78	2.38	2.47	2.34	3.09	2.51	2.29
Omphalocele	2.51	1.83	2.13	1.88	2.26	2.27	2.40
Gastroschisis	1.23	1.32	1.95	1.94	2.93	2.61	3.00
Unspecified Omphalocele / Gastroschisis	nr	nr	nr	nr	nr	0.62	0.60*
Prune belly sequence	nr	nr	nr	nr	nr	1.27	1.89
Trisomy 13	nr	nr	nr	nr	nr	1.41	1.86
Trisomy 18	nr	nr	nr	nr	nr	3.33	4.08
Down syndrome, all ages (include age unknown)	9.44	10.40	10.85	10.47	11.47	16.17	17.31
<20	1.46	4.85	4.67	1.60	3.41	6.91	7.80*
20-24	5.98	7.05	6.91	5.97	3.69	4.78	5.91
25-29	8.14	7.10	5.80	7.13	5.98	8.07	8.68
30-34	10.26	12.53	14.96	11.80	10.56	12.30	12.88
35-39	33.91	35.53	36.95	25.06	33.15	42.27	44.19
40-44	128.11	104.22	63.85	82.90	108.54	135.07	136.75
45+	182.93	94.34	294.12	416.67	138.89	343.14	216.72
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

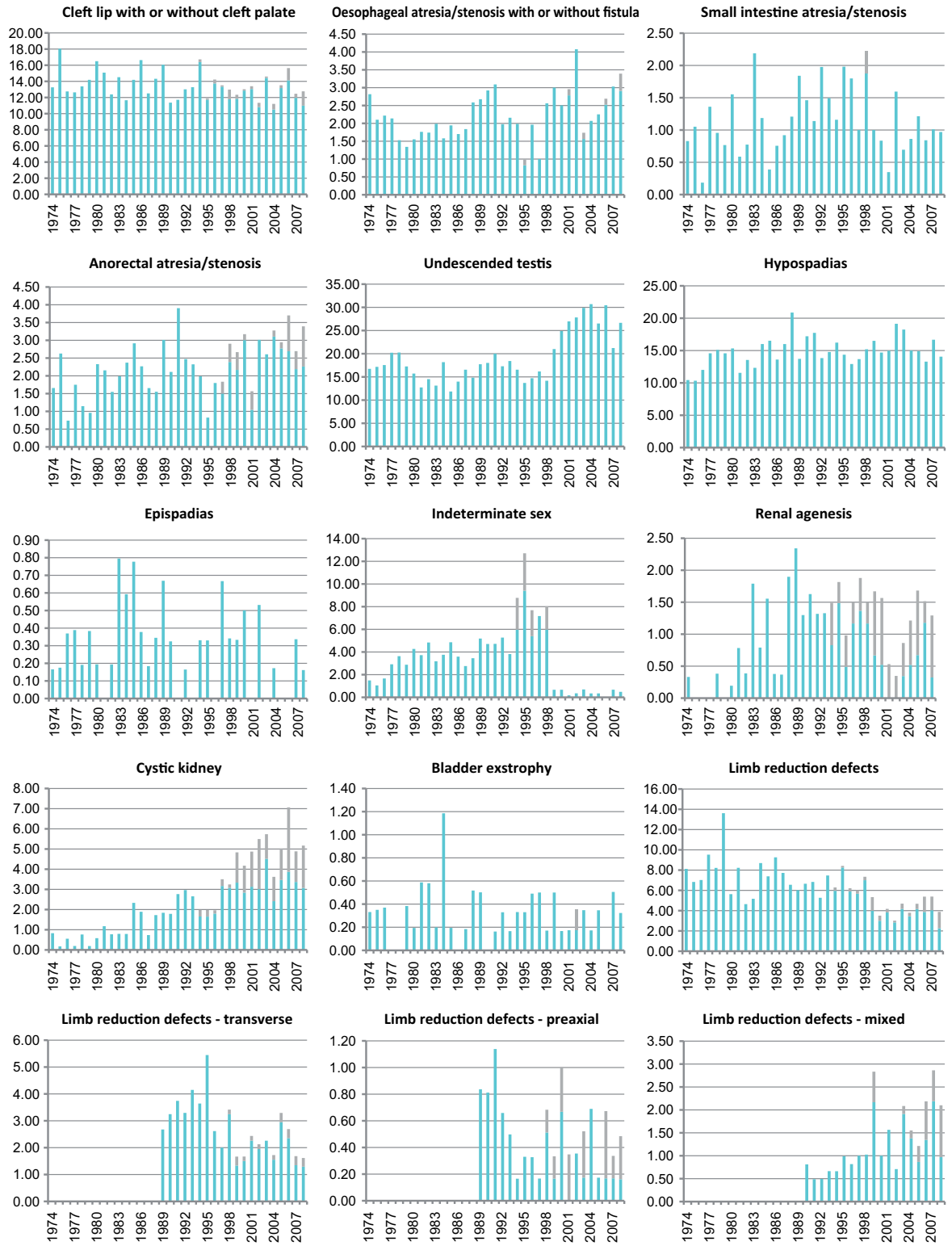
Norway: MBRN

Time trends 1974-2008 (Birth prevalence rates per 10,000)



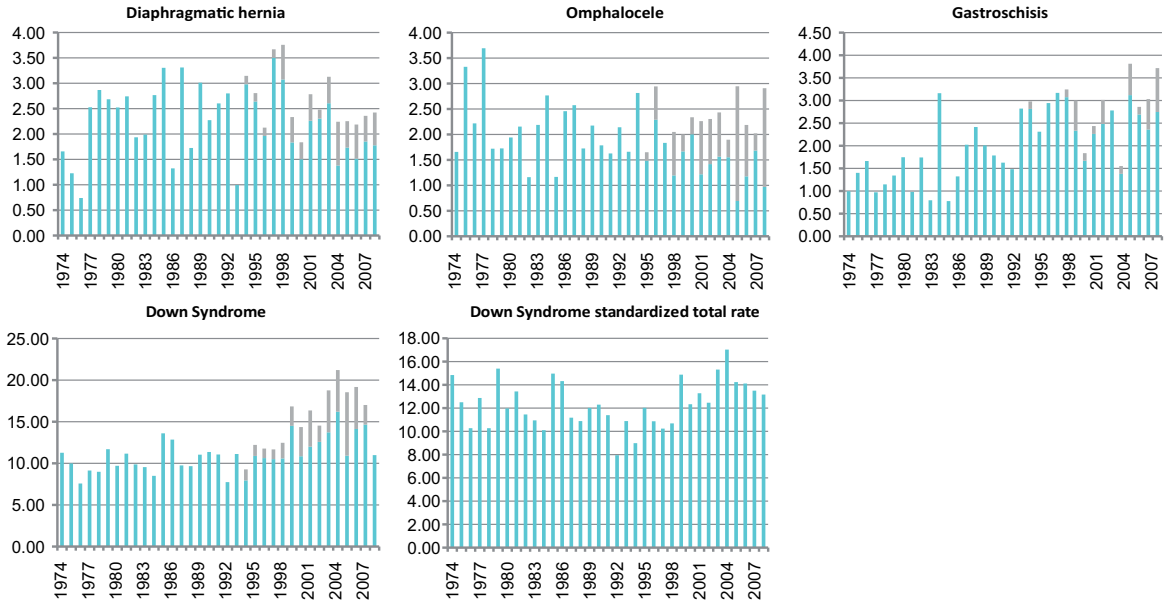
Note: L+S rates, ToP rates

Norway: MBRN



Note: L+S rates, ToP rates

Norway: MBRN



Note: L+S rates, ToP rates

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:
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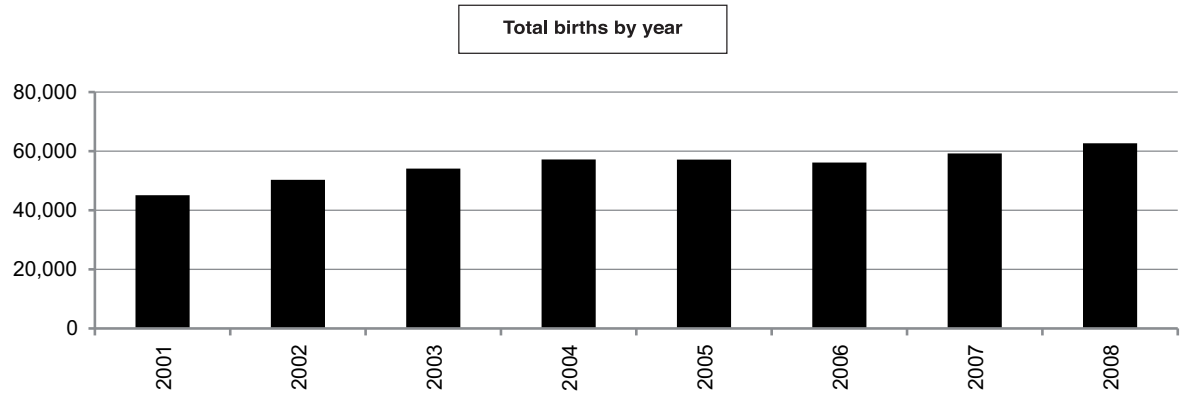
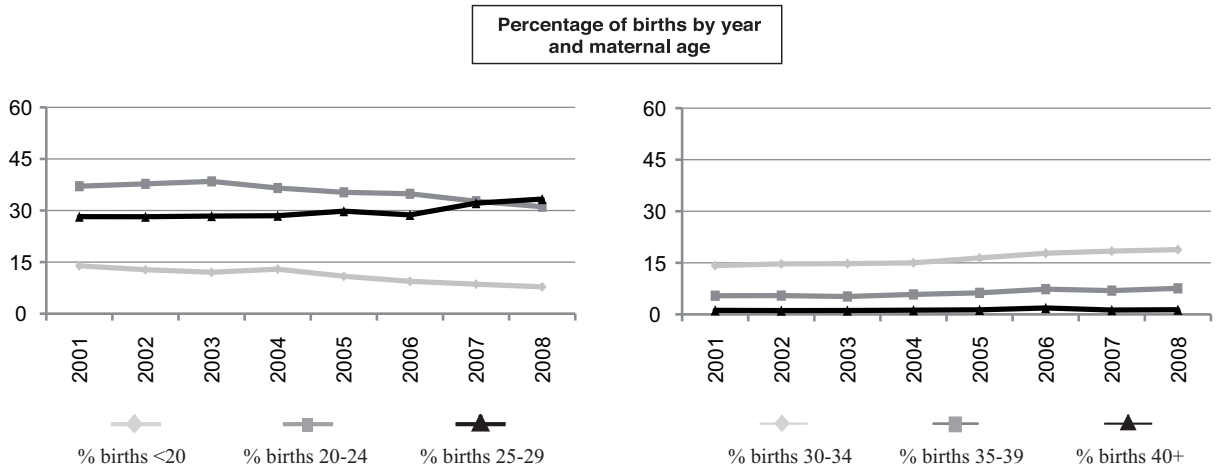
22a, Pokrovka St.
101000 Moscow Russia
Phone: 007-0959356228
Fax: 007-0959215398
E-mail: mrrcm@mail.ru

Russia: MRRCM





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	36	80.0	Cystic kidney	18	27.3
Spina bifida	23	28.8	Limb reduction defects	6	11.1
Encephalocele	6	42.9	Diaphragmatic hernia	6	16.7
Holoprosencephaly	7	77.8	Omphalocele	14	33.3
Hydrocephaly	33	32.0	Gastroschisis	30	40.5
Hypoplastic left heart syndrome	10	35.7	Trisomy 13	1	100.0
Cleft palate without cleft lip	1	1.4	Trisomy 18	5	41.7
Cleft lip with or without cleft palate	9	8.5	Down syndrome	33	12.4
Renal agenesis	10	27.8			

Total ToPs with births defects = 589 (Ratio ToPs/Births: 3.31 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Russia: MRRCM, 2008

Live births (LB)	62,369
Stillbirths (SB)	299
Total births	62,668
Number of terminations of pregnancy (ToP) for birth defects	211

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	10	1.91
Spina bifida	10	nr	7	2.71
Encephalocele	nr	nr	nr	nr
Microcephaly	3	nr	1	0.64
Holoprosencephaly	nr	nr	5	0.80
Hydrocephaly	21	3	7	4.95
Anophthalmos	1	nr	nr	0.16
Microphthalmos	nr	nr	nr	nr
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	nr	nr	0.16
Microtia	1	nr	nr	0.16
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	4	nr	nr	0.64
Tetralogy of Fallot	6	nr	5	1.76
Hypoplastic left heart syndrome	4	nr	3	1.12
Coarctation of aorta	4	nr	nr	0.64
Choanal atresia, bilateral	1	nr	nr	0.16
Cleft palate without cleft lip	25	nr	1	4.15
Cleft lip with or without cleft palate	19	nr	2	3.35
Oesophageal atresia/stenosis with or without fistula	7	nr	nr	1.12
Small intestine atresia/stenosis	11	nr	nr	1.76
Anorectal atresia/stenosis	6	nr	nr	0.96
Undescended testis (36 weeks of gestation or later)	87	nr	nr	13.88
Hypospadias	90	nr	nr	14.36
Epispadias	4	nr	nr	0.64
Indeterminate sex	nr	nr	nr	0.00
Renal agenesis	3	1	nr	0.64
Cystic kidney	13	nr	7	3.19
Bladder exstrophy	nr	nr	nr	nr
Polydactyly, preaxial	12	nr	nr	1.91
Total Limb reduction defects (include unspecified)	19	nr	2	3.35
Transverse	14	nr	nr	2.23
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	1	nr	nr	0.16
Mixed	nr	nr	nr	nr
Unspecified	4	nr	nr	0.64
Diaphragmatic hernia	5	nr	3	1.28
Omphalocele	5	nr	5	1.60
Gastroschisis	15	1	8	3.83
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	3	0.48
Trisomy 13	nr	nr	nr	nr
Trisomy 18	3	nr	1	0.64
Down syndrome, all ages (include age unknown)	91	2	21	18.19
<20	2	nr	1	6.13
20-24	8	nr	4	6.16
25-29	22	2	4	13.41
30-34	23	nr	2	21.18
35-39	25	nr	7	67.40
40-44	10	nr	3	161.09
45+	nr	nr	nr	0.00
unknown	1	nr	nr	---

nr = not reported

Russia: MRRCM, Previous years rates 2001 - 2008

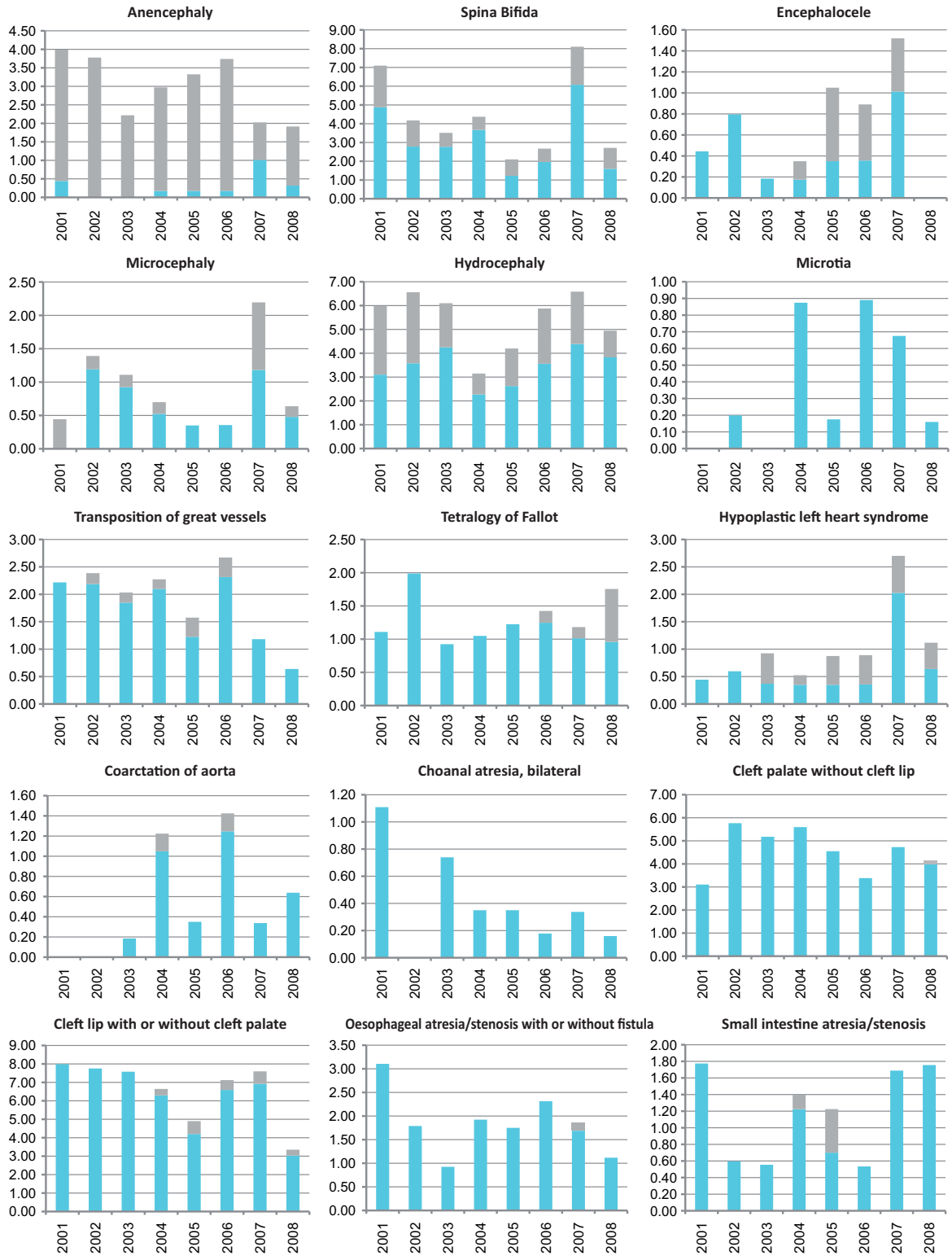
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003*	2004-2008
Total births						**149,495**	**292,389**
Anencephaly						3.28	2.77
Spina bifida						4.82	4.00
Encephalocele						0.47	0.96*
Microcephaly						1.00	0.86
Holoprosencephaly						0.13	0.44
Hydrocephaly						6.22	4.96
Anophthalmos						0.13	0.10
Microphthalmos						0.00	0.17*
Unspecified Anophthalmos / Microphthalmos						0.00	0.00*
Anotia						0.00	0.38
Microtia						0.07	0.55
Unspecified Anotia / Microtia						0.94	0.00*
Transposition of great vessels						2.21	1.64
Tetralogy of Fallot						1.34	1.33
Hypoplastic left heart syndrome						0.67	1.23
Coarctation of aorta						0.07	0.79
Choanal atresia, bilateral						0.60	0.27
Cleft palate without cleft lip						4.75	4.48
Cleft lip with or without cleft palate						7.76	5.88
Oesophageal atresia / stenosis with or without fistula						1.87	1.78
Small intestine atresia / stenosis						0.94	1.33
Anorectal atresia / stenosis						2.34	2.09
Undescended testis (36 weeks of gestation or later)						23.35	14.50
Hypospadias						16.79	13.75
Epispadias						0.20	0.17
Indeterminate sex						0.54	0.48*
Renal agenesis						1.61	1.64
Cystic kidney						2.47	3.56
Bladder exstrophy						0.20	0.13*
Polydactyly, preaxial						7.89	4.34
Total Limb reduction defects (include unspecified)						4.01	2.60
Transverse						1.27	1.71
Preaxial						0.40	0.22*
Postaxial						0.27	0.04*
Intercalary						0.13	0.07
Mixed						0.54	0.58*
Unspecified						1.40	0.64*
Diaphragmatic hernia						1.40	1.92
Omphalocele						4.28	2.09
Gastroschisis						2.74	3.63
Unspecified Omphalocele / Gastroschisis						1.81	0.00*
Prune belly sequence						0.07	0.10
Trisomy 13						0.20	0.13*
Trisomy 18						0.27	0.51
Down syndrome, all ages (include age unknown)						11.97	14.23
<20						6.76	5.54
20-24						7.26	6.84
25-29						6.63	9.73
30-34						13.32	18.16
35-39						48.71	46.31
40-44						134.31	146.02
45+						937.50	131.58
unknown						---	---

* data include less than 5 years

Russia: MRRCM

Time trends 2001-2008 (Birth prevalence rates per 10,000)

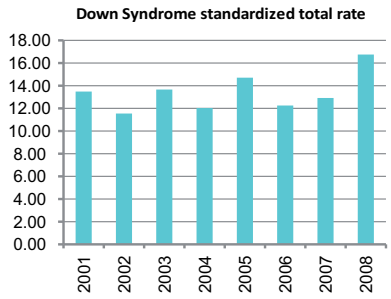


Note: L+S rates, ToP rates

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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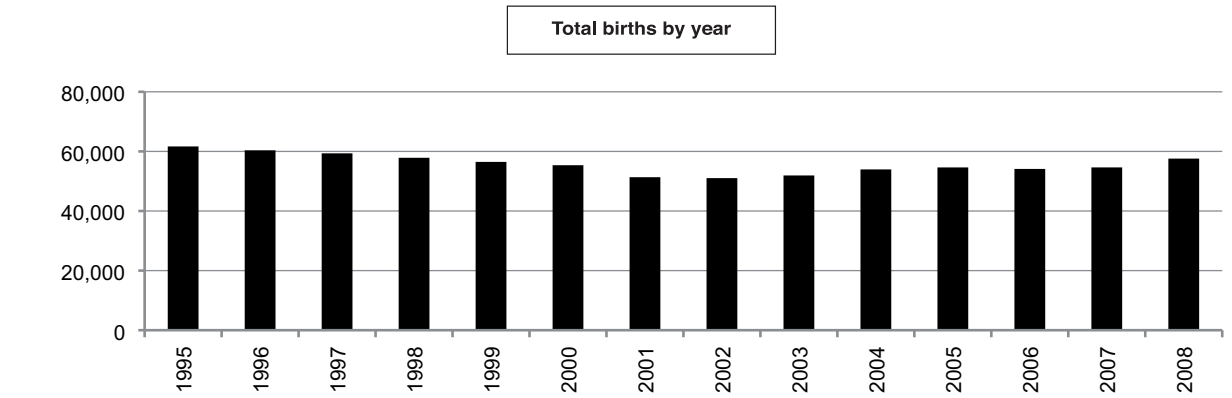
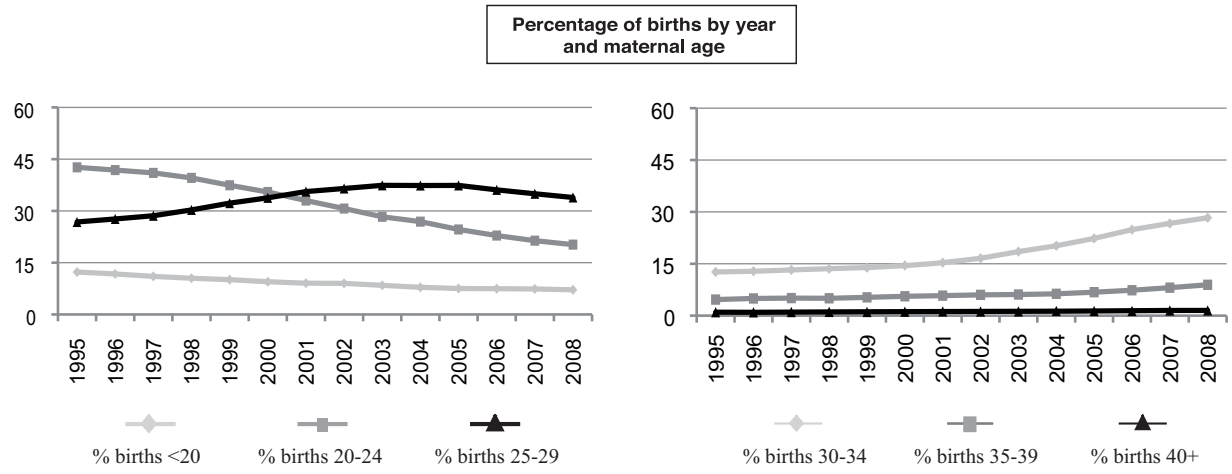
Slovak Republic





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	13	86.7	Cystic kidney	1	4.8
Spina bifida	5	14.7	Limb reduction defects	0	0.0
Encephalocele	4	40.0	Diaphragmatic hernia	0	0.0
Holoprosencephaly	0	0.0	Omphalocele	0	0.0
Hydrocephaly	11	20.8	Gastroschisis	1	5.9
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	1	25.0
Cleft palate without cleft lip	1	1.3	Trisomy 18	0	0.0
Cleft lip with or without cleft palate	0	0.0	Down syndrome	31	21.4
Renal agenesis	0	0.0			

Total ToPs with births defects = 115 (Ratio ToPs/Births: 0.69 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Slovak Republic, 2008

Live births (LB)	57,360
Stillbirths (SB)	226
Total births	57,586
Number of terminations of pregnancy (ToP) for birth defects	50

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	2	0.52
Spina bifida	14	0	0	2.43
Encephalocele	2	0	0	0.35
Microcephaly	3	0	2	0.87
Holoprosencephaly	1	0	0	0.17
Hydrocephaly	7	0	5	2.08
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.17
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	0	0	0	0.00
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	1	0	0	0.17
Transposition of great vessels	6	0	0	1.04
Tetralogy of Fallot	9	0	0	1.56
Hypoplastic left heart syndrome	9	0	0	1.56
Coarctation of aorta	1	0	0	0.17
Choanal atresia, bilateral	3	0	0	0.52
Cleft palate without cleft lip	24	0	0	4.17
Cleft lip with or without cleft palate	37	1	0	6.60
Oesophageal atresia/stenosis with or without fistula	5	0	0	0.87
Small intestine atresia/stenosis	12	0	0	2.08
Anorectal atresia/stenosis	11	0	0	1.91
Undescended testis (36 weeks of gestation or later)	58	0	0	10.07
Hypospadias	104	0	0	18.06
Epispadias	1	0	0	0.17
Indeterminate sex	2	0	0	0.35
Renal agenesis	30	0	0	5.21
Cystic kidney	5	0	0	0.87
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	13	0	0	2.26
Total Limb reduction defects (include unspecified)	12	0	0	2.08
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	12	0	0	2.08
Diaphragmatic hernia	8	1	0	1.56
Omphalocele	3	0	0	0.52
Gastroschisis	4	0	0	0.69
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	0	0.00
Trisomy 18	5	0	0	0.87
Down syndrome, all ages (include age unknown)	43	0	19	10.77
<20	1	0	0	nr
20-24	4	0	1	nr
25-29	12	0	1	nr
30-34	12	0	6	nr
35-39	9	0	10	nr
40-44	5	0	1	nr
45+	0	0	0	nr
unknown	0	0	0	---

nr = not reported

Slovak Republic, Previous years rates 1995 - 2008

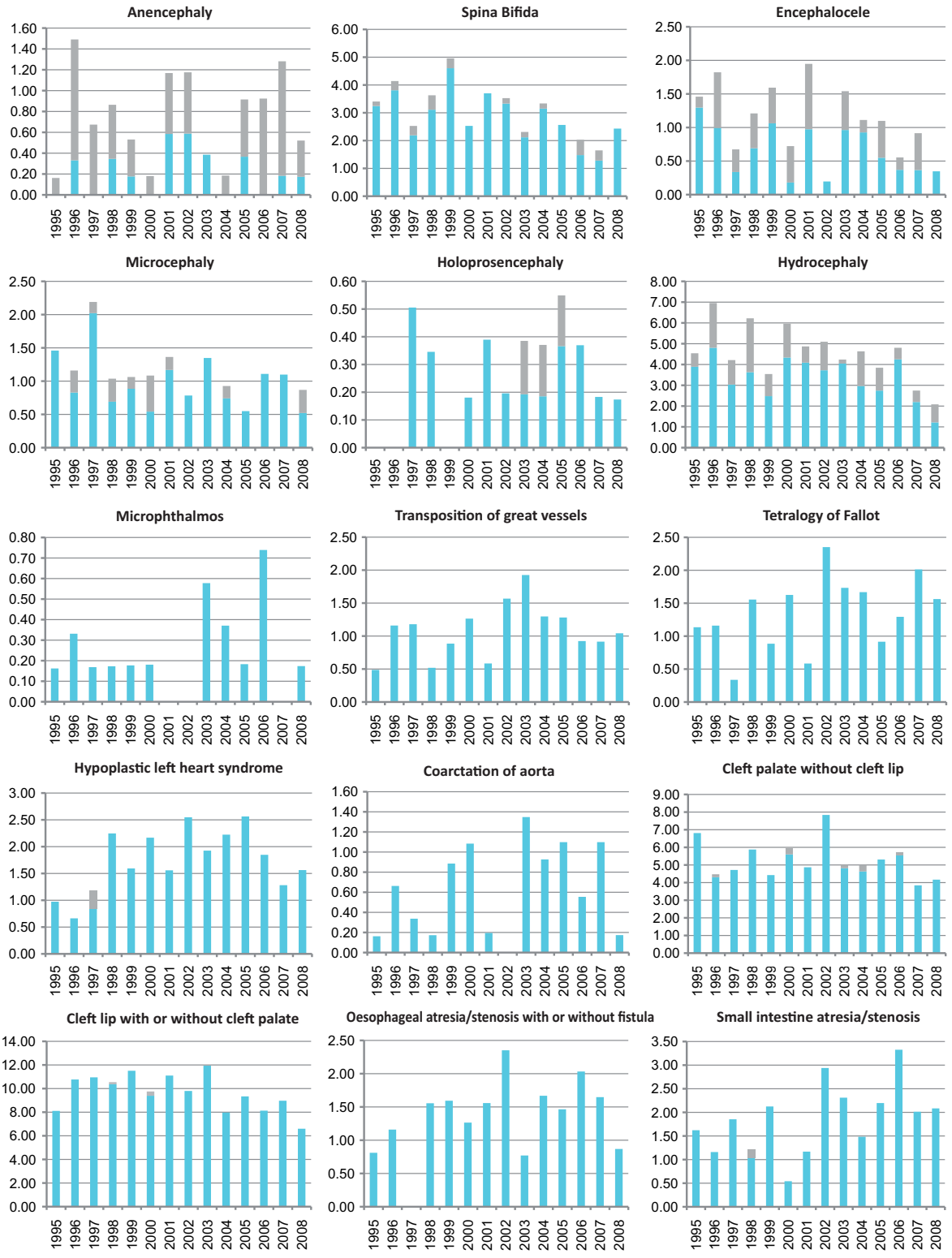
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998*	1999-2003	2004-2008
Total births					**239,250**	**266,156**	**274,922**
Anencephaly					0.79	0.68	0.76
Spina bifida					3.43	3.42	2.40
Encephalocele					1.30	1.20	0.80
Microcephaly					1.46	1.13	0.91
Holoprosencephaly					0.21	0.23	0.33
Hydrocephaly					5.48	4.73	3.60
Anophthalmos					0.04	0.08	0.04
Microphthalmos					0.21	0.19	0.29
Unspecified Anophthalmos / Microphthalmos					0.00	0.00	0.00*
Anotia					0.08	0.19	0.04
Microtia					0.33	0.30	0.18
Unspecified Anotia / Microtia					0.21	0.45	0.51
Transposition of great vessels					0.84	1.24	1.09
Tetralogy of Fallot					1.04	1.43	1.49
Hypoplastic left heart syndrome					1.25	1.95	1.89
Coarctation of aorta					0.33	0.71	0.76
Choanal atresia, bilateral					0.21	0.15	0.29
Cleft palate without cleft lip					5.48	5.60	4.80
Cleft lip with or without cleft palate					10.07	10.82	8.18
Oesophageal atresia / stenosis with or without fistula					0.88	1.50	1.53
Small intestine atresia / stenosis					1.46	1.80	2.22
Anorectal atresia / stenosis					1.34	2.89	2.66
Undescended testis (36 weeks of gestation or later)					5.85	7.78	9.49
Hypospadias					23.78	22.28	20.30
Epispadias					0.17	0.19	0.18
Indeterminate sex					0.50	0.38	0.25
Renal agenesis					2.05	5.30	5.78
Cystic kidney					0.84	1.43	1.31
Bladder exstrophy					0.08	0.23	0.07
Polydactyly, preaxial					1.34	3.27	2.73
Total Limb reduction defects (include unspecified)					3.76	3.49	3.35
Transverse					nr	nr	nr
Preaxial					nr	nr	nr
Postaxial					nr	nr	nr
Intercalary					nr	nr	nr
Mixed					nr	nr	nr
Unspecified					3.76	3.49	3.35
Diaphragmatic hernia					1.25	1.58	1.49
Omphalocele					0.63	0.60	0.58
Gastroschisis					0.79	1.16	0.87
Unspecified Omphalocele / Gastroschisis					0.00	0.00	0.00*
Prune belly sequence					0.00	0.15	0.15
Trisomy 13					0.08	0.56	0.22
Trisomy 18					0.21	0.45	0.55
Down syndrome, all ages (include age unknown)					8.86	10.75	9.02
<20					5.86	6.92	1.95
20-24					6.17	4.88	4.09
25-29					6.20	7.29	5.78
30-34					12.81	12.67	9.80
35-39					31.43	45.78	29.11
40-44					59.57	107.24	86.42
45+					208.33	252.10	168.54
unknown					---	---	---

nr = not reported
* data include less than 5 years

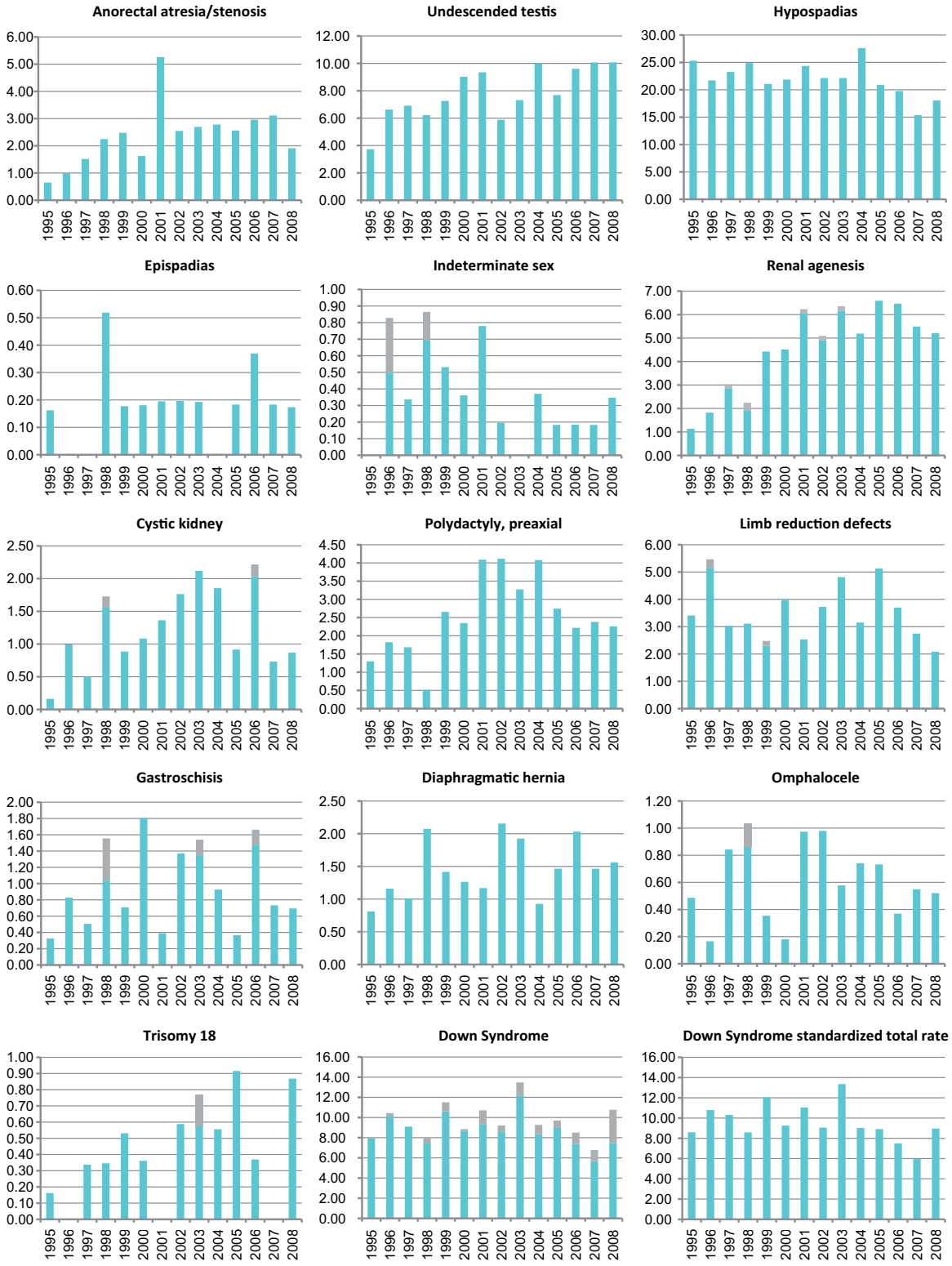
Slovak Republic

Time trends 1995-2008 (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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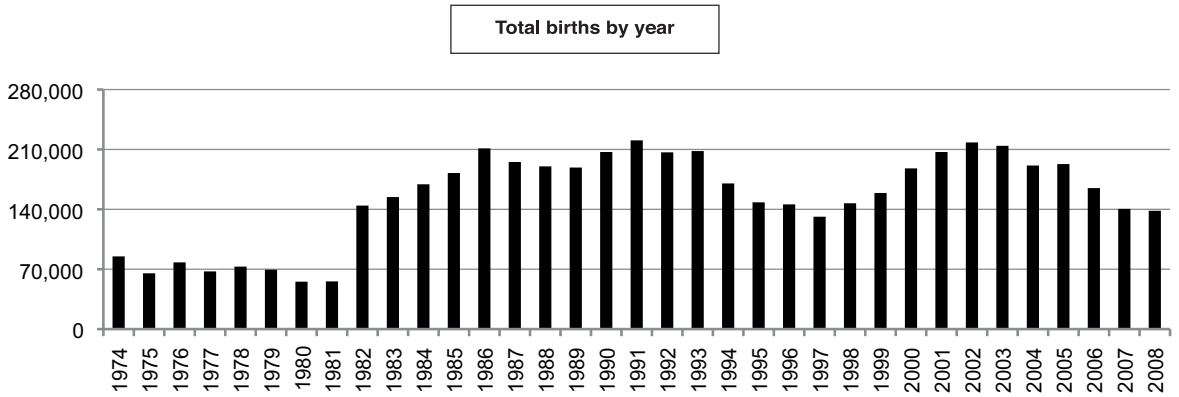
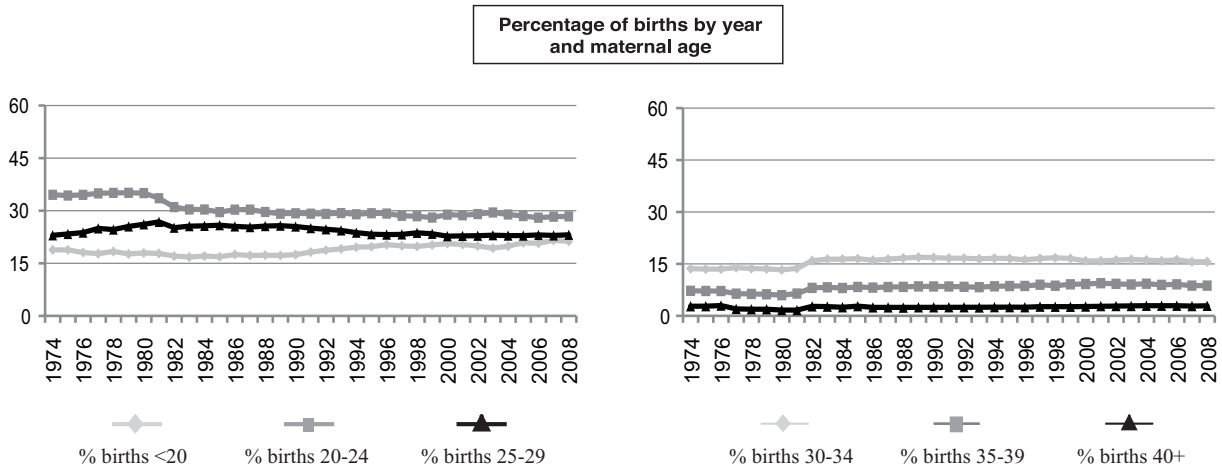
South America: ECLAMC





South America: ECLAMC, 2008

Live births (LB)	136,711
Stillbirths (SB)	1,596
Total births	138,307
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	45	36		5.86
Spina bifida	106	11		8.46
Encephalocele	32	7		2.82
Microcephaly	56	3		4.27
Holoprosencephaly	8	6		1.01
Hydrocephaly	218	22		17.35
Anophthalmos	13	3		1.16
Microphthalmos	17	6		1.66
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	2	0		0.14
Microtia	77	4		5.86
Unspecified Anotia/Microtia	3	0		0.22
Transposition of great vessels	7	1		0.58
Tetralogy of Fallot	28	0		2.02
Hypoplastic left heart syndrome	16	1		1.23
Coarctation of aorta	6	3		0.65
Choanal atresia, bilateral	5	0		0.36
Cleft palate without cleft lip	59	1		4.34
Cleft lip with or without cleft palate	124	25		10.77
Oesophageal atresia/stenosis with or without fistula	45	2		3.40
Small intestine atresia/stenosis	53	2		3.98
Anorectal atresia/stenosis	67	11		5.64
Undescended testis (36 weeks of gestation or later)	116	1		8.46
Hypospadias	119	2		8.75
Epispadias	0	0		0.00
Indeterminate sex	21	8		2.10
Renal agenesis	34	4		2.75
Cystic kidney	57	6		4.56
Bladder exstrophy	2	0		0.14
Polydactyly, preaxial	42	3		3.25
Total Limb reduction defects (include unspecified)	100	10		7.95
Transverse	31	0		2.24
Preaxial	12	3		1.08
Postaxial	11	0		0.80
Intercalary	15	2		1.23
Mixed	30	5		2.53
Unspecified	1	0		0.07
Diaphragmatic hernia	45	3		3.47
Omphalocele	45	19		4.63
Gastroschisis	116	6		8.82
Unspecified Omphalocele/Gastroschisis	5	0		0.36
Prune belly sequence	9	1		0.72
Trisomy 13	2	5		0.51
Trisomy 18	18	9		1.95
Down syndrome, all ages (include age unknown)	242	6		17.93
<20	29	0		10.02
20-24	37	0		9.57
25-29	28	2		9.52
30-34	35	1		16.93
35-39	57	2		49.63
40-44	44	1		122.55
45+	12	0		425.53
unknown	0	0		---

South America: ECLAMC, Previous years rates 1974 - 2008

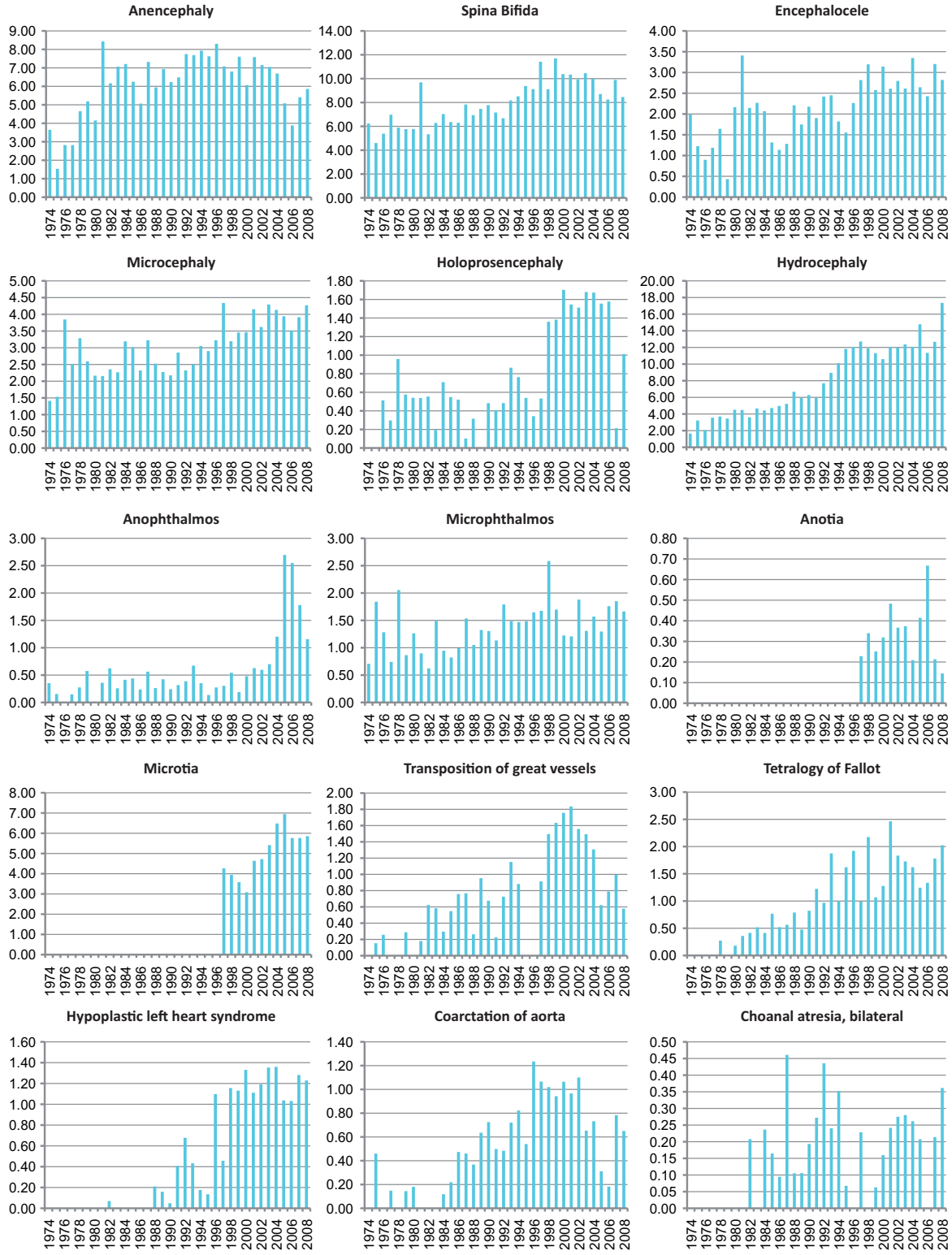
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**368,640**	**479,280**	**948,406**	**1,031,139**	**742,650**	**986,382**	**827,692**
Anencephaly	3.15	6.34	6.32	7.01	7.57	7.09	5.40
Spina bifida	5.83	6.26	6.89	7.45	9.44	10.50	9.07
Encephalocele	1.41	2.09	1.58	2.14	2.30	2.75	2.89
Microcephaly	2.52	2.32	2.84	2.43	3.31	3.82	3.95
Holoprosencephaly	0.35	0.44	0.43	0.46	0.71	1.57	1.27
Hydrocephaly	2.77	4.13	5.22	6.96	11.65	11.71	13.54
Anophthalmos	0.19	0.40	0.38	0.41	0.32	0.54	1.91
Microphthalmos	1.30	1.04	1.08	1.41	1.76	1.46	1.61
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	0.29*	0.36	0.34
Microtia	nr	nr	nr	nr	4.09*	4.36	6.22
Unspecified Anotia / Microtia	nr	nr	nr	nr	0.04*	0.08	0.14
Transposition of great vessels	0.08	0.44	0.54	0.74	0.82*	1.65	0.87
Tetralogy of Fallot	0.05	0.35	0.61	1.09	1.54	1.71	1.57
Hypoplastic left heart syndrome	0.00	0.02	0.04	0.35	0.59	1.23	1.18
Coarctation of aorta	0.11	0.04	0.34	0.61	0.93	0.94	0.52
Choanal atresia, bilateral	0.00	0.06	0.21	0.25	0.13	0.21	0.21
Cleft palate without cleft lip	3.36	3.30	3.22	3.62	3.90	4.61	5.03
Cleft lip with or without cleft palate	11.01	10.56	10.90	10.18	12.00	13.43	13.62
Oesophageal atresia / stenosis with or without fistula	2.01	2.36	2.57	2.89	3.23	3.65	3.55
Small intestine atresia / stenosis	0.43	1.52	1.47	1.75	1.87	2.85	3.31
Anorectal atresia / stenosis	2.60	3.86	3.48	4.41	4.74	5.57	5.53
Undescended testis (36 weeks of gestation or later)	1.41	2.84	4.59	4.60	5.10	6.56	8.96
Hypospadias	3.69	4.01	4.56	4.06	5.00	5.16	6.23
Epispadias	0.16	0.25	0.33	0.36	0.19	0.21	0.16
Indeterminate sex	1.00	1.96	2.17	1.76	1.71	2.24	2.63
Renal agenesis	0.43	0.63	0.76	1.52	2.06	2.37	2.72
Cystic kidney	0.62	0.79	1.49	1.84	3.39	4.28	3.85
Bladder exstrophy	0.14	0.19	0.28	0.23	0.38	0.34	0.25
Polydactyly, preaxial	3.09	2.15	2.44	2.73	2.85	3.69	3.99
Total Limb reduction defects (include unspecified)	4.10	5.57	4.83	5.23	6.19	6.60	8.06
Transverse	2.03	2.61	2.69	2.62	3.11	3.52	2.75
Preaxial	0.62	1.13	0.98	0.99	1.48	1.54	1.26
Postaxial	0.24	0.58	0.24	0.46	0.38	0.41	0.53
Intercalary	0.57	0.63	0.35	0.48	0.47	0.46	0.86
Mixed	0.52	0.54	0.44	0.58	0.61	0.46	2.20
Unspecified	0.11	0.08	0.13	0.11	0.15	0.22	0.46
Diaphragmatic hernia	0.57	1.44	1.52	1.99	3.39	3.93	3.52
Omphalocele	1.06	1.90	2.22	2.35	3.10	3.35	4.25
Gastroschisis	0.05	0.31	0.67	0.93	2.37	3.03	6.39
Unspecified Omphalocele / Gastroschisis	0.33	0.42	0.36	0.47	0.96	1.42	0.62
Prune belly sequence	0.03	0.46	0.66	0.75	1.10	1.09	0.80
Trisomy 13	0.16	0.38	0.53	0.46	0.89	0.90	0.60
Trisomy 18	0.27	0.54	0.98	0.90	1.64	2.15	1.57
Down syndrome, all ages (include age unknown)	14.38	14.90	15.03	15.49	17.77	19.11	19.05
<20	7.38	7.20	6.72	6.79	8.08	7.11	9.20
20-24	7.32	7.18	6.45	7.84	8.33	9.56	9.04
25-29	7.24	7.90	7.32	8.34	9.68	10.18	9.46
30-34	12.49	17.08	15.56	15.36	16.48	17.01	17.03
35-39	56.73	47.71	43.27	45.90	50.73	55.80	52.87
40-44	152.66	149.92	155.47	140.61	181.56	167.56	174.26
45+	260.99	299.79	274.29	253.44	303.29	387.17	377.73
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

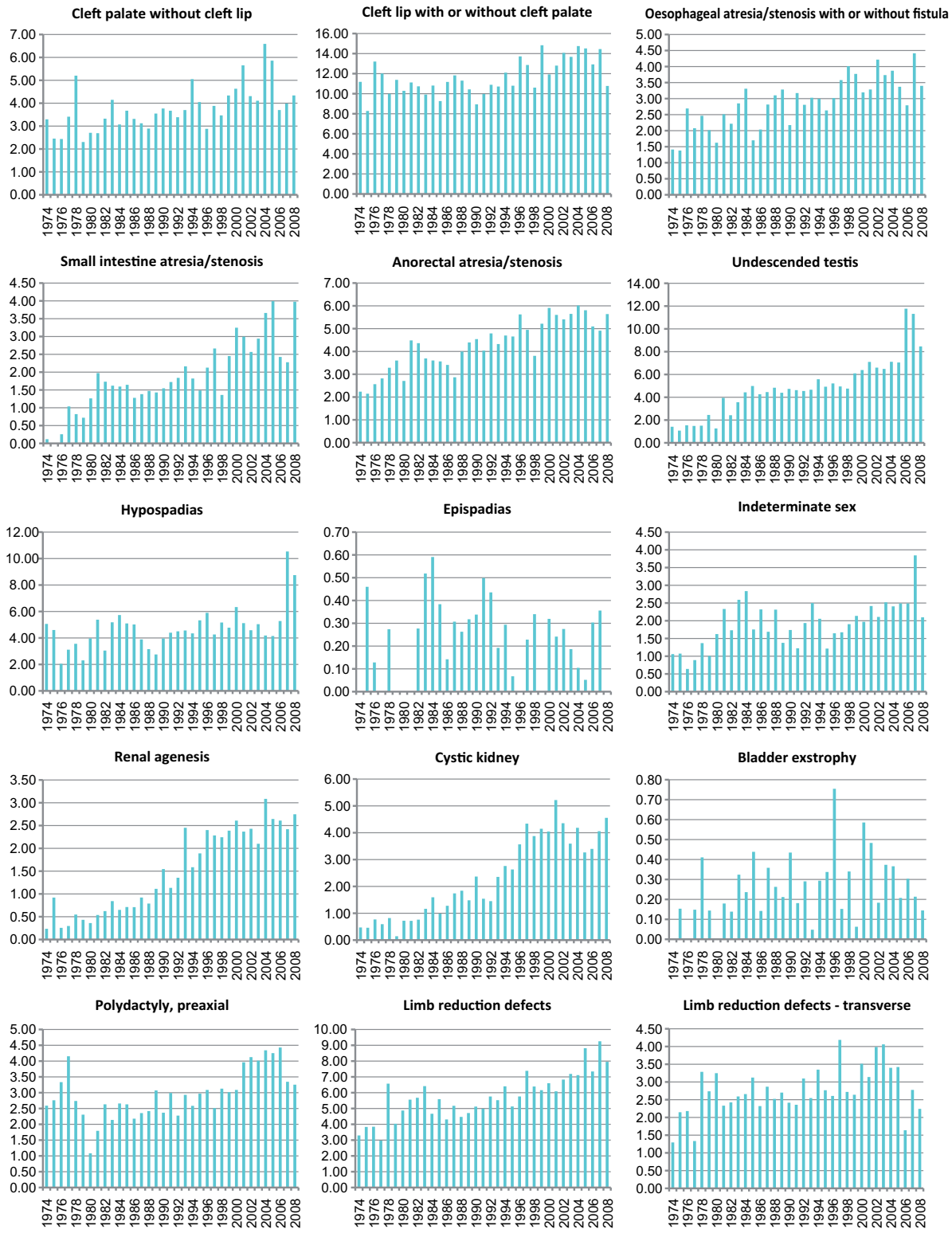
South America: ECLAMC

Time trends 1974-2008 (Birth prevalence rates per 10,000)



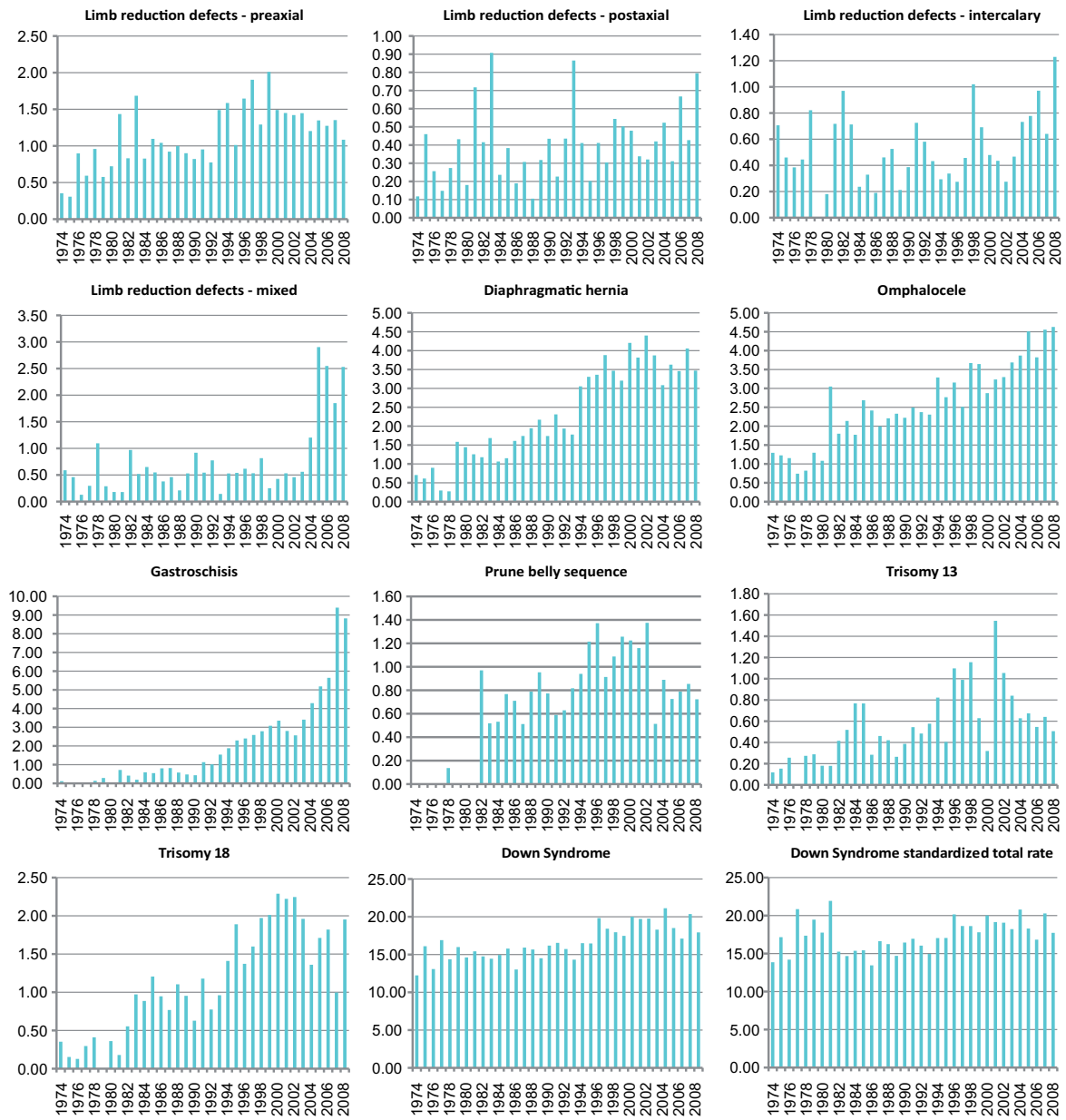
Note: L+S rates

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 contributes to EUROCAT 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) from the Ministerio de Sanidad y Consumo of Spain and since 2008 from the Ministerio de Ciencia e Innovación. It is also directed by Prof. Martínez-Frías. In 2006 the ECEMC was recognized as an excellence Research programme to be integrated into the CIBERER (Centre for Biomedical Research on Rare Diseases). The ECEMC has 2 Teratogen Information Services since 1991, one for the general population and another one for physicians.

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 within the first 22 weeks of gestation, can only be gathered in some participating hospitals.

Legislation and funding:
It is a research programme with voluntary participation of hospitals (but mandatory subjugation to the Operating Rules for those participating), and is financed mainly by the Spanish Administration and, partially, by non-governmental organisations.

Sources of ascertainment:
The detection period is the first 3 days of life, including major and/or minor/mild defects. 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. 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. 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 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, 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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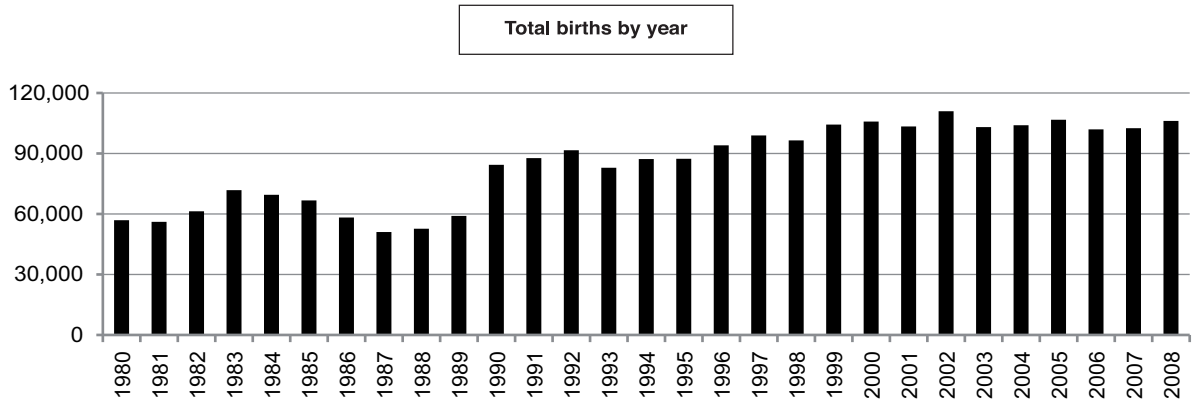
Spain: ECEMC


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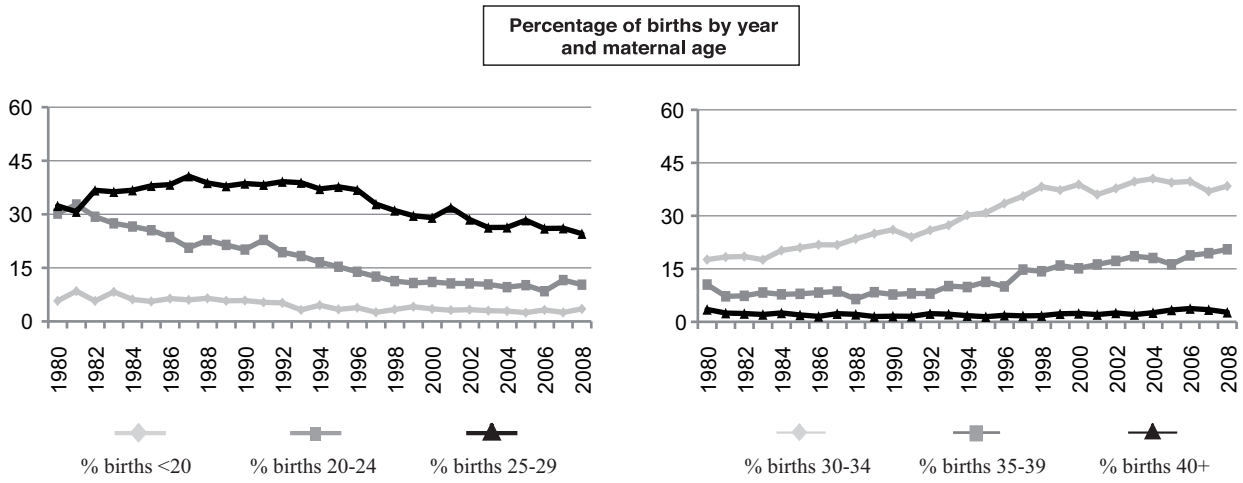
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008


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, 2008

Live births (LB)	105,752
Stillbirths (SB)	399
Total births	106,151
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	1	nr	0.28
Spina bifida	7	0	nr	0.66
Encephalocele	1	0	nr	0.09
Microcephaly	7	0	nr	0.66
Holoprosencephaly	5	1	nr	0.57
Hydrocephaly	17	2	nr	1.79
Anophthalmos	2	1	nr	0.28
Microphthalmos	14	0	nr	1.32
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	1	0	nr	0.09
Microtia	10	0	nr	0.94
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	6	1	nr	0.66
Tetralogy of Fallot	4	1	nr	0.47
Hypoplastic left heart syndrome	0	0	nr	0.00
Coarctation of aorta	13	0	nr	1.22
Choanal atresia, bilateral	1	0	nr	0.09
Cleft palate without cleft lip	37	1	nr	3.58
Cleft lip with or without cleft palate	31	0	nr	2.92
Oesophageal atresia/stenosis with or without fistula	12	0	nr	1.13
Small intestine atresia/stenosis	7	0	nr	0.66
Anorectal atresia/stenosis	18	0	nr	1.70
Undescended testis (36 weeks of gestation or later)	16	0	nr	1.51
Hypospadias	16	0	nr	1.51
Epispadias	1	0	nr	0.09
Indeterminate sex	5	0	nr	0.47
Renal agenesis	1	1	nr	0.19
Cystic kidney	19	1	nr	1.88
Bladder exstrophy	0	0	nr	0.00
Polydactyly, preaxial	13	0	nr	1.22
Total Limb reduction defects (include unspecified)	41	0	nr	3.86
Transverse	15	0	nr	1.41
Preaxial	7	0	nr	0.66
Postaxial	1	0	nr	0.09
Intercalary	2	0	nr	0.19
Mixed	7	0	nr	0.66
Unspecified	9	0	nr	0.85
Diaphragmatic hernia	9	2	nr	1.04
Omphalocele	2	1	nr	0.28
Gastroschisis	8	0	nr	0.75
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	2	0	nr	0.19
Trisomy 13	2	1	nr	0.28
Trisomy 18	9	2	nr	1.04
Down syndrome, all ages (include age unknown)	67	1	nr	6.41
<20	3	0	nr	8.06
20-24	4	0	nr	3.66
25-29	7	0	nr	2.68
30-34	16	0	nr	3.92
35-39	22	0	nr	10.10
40-44	13	0	nr	47.17
45+	2	0	nr	181.82
unknown	0	1	nr	---

nr = not reported

Spain: ECEMC, Previous years rates 1980 - 2008

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

	1974-1978	1979-1983*	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**246,157**	**298,215**	**405,665**	**464,090**	**527,615**	**521,388**	
Anencephaly	4.59	3.55	1.21	0.80	0.15	0.31	
Spina bifida	4.22	4.93	3.82	2.48	1.38	1.02	
Encephalocele	1.30	0.60	1.01	0.39	0.15	0.21	
Microcephaly	2.11	2.11	2.29	1.77	1.29	0.94	
Holoprosencephaly	0.41	0.54	0.57	0.56	0.25	0.36	
Hydrocephaly	2.60	2.58	2.71	2.87	1.80	2.09	
Anophthalmos	0.81	0.40	0.35	0.17	0.11	0.21	
Microphthalmos	1.83	1.98	1.90	1.40	0.95	1.00	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	0.00	0.03	0.10	0.19	0.09	0.08	
Microtia	1.91	1.94	1.58	1.42	1.52	1.32	
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	0.65	0.77	1.33	1.44	1.14	1.11	
Tetralogy of Fallot	0.16	0.23	1.06	1.16	1.04	0.73	
Hypoplastic left heart syndrome	0.37	0.34	0.81	0.69	0.32	0.19	
Coarctation of aorta	0.41	0.30	0.79	0.90	0.68	0.92	
Choanal atresia, bilateral	0.16	0.30	0.27	0.22	0.13	0.23	
Cleft palate without cleft lip	5.48	4.02	5.30	4.01	3.85	3.82	
Cleft lip with or without cleft palate	5.69	5.57	5.69	4.85	3.64	3.57	
Oesophageal atresia / stenosis with or without fistula	2.27	1.78	2.24	1.85	1.78	1.78	
Small intestine atresia / stenosis	0.49	0.54	0.62	0.32	0.59	0.58	
Anorectal atresia / stenosis	2.60	2.38	2.02	2.07	2.05	1.96	
Undescended testis (36 weeks of gestation or later)	1.83	2.38	2.64	2.87	2.46	2.11	
Hypospadias	2.72	2.58	2.10	1.53	2.22	1.61	
Epispadias	0.28	0.13	0.25	0.06	0.09	0.06	
Indeterminate sex	0.81	1.11	0.94	0.58	0.63	0.40	
Renal agenesis	0.61	0.84	0.71	0.56	0.09	0.10	
Cystic kidney	1.26	1.27	1.77	1.72	1.42	1.73	
Bladder exstrophy	0.20	0.30	0.30	0.30	0.17	0.21	
Polydactyly, preaxial	2.40	2.65	3.35	2.59	1.95	2.32	
Total Limb reduction defects (include unspecified)	7.56	6.40	7.07	5.97	4.80	4.45	
Transverse	3.13	2.82	2.74	2.24	1.95	1.80	
Preaxial	1.30	1.04	1.04	0.65	0.61	0.61	
Postaxial	0.12	0.20	0.15	0.24	0.13	0.12	
Intercalary	0.61	0.27	0.59	0.26	0.30	0.21	
Mixed	1.14	1.01	1.18	1.03	0.97	0.92	
Unspecified	1.26	1.07	1.38	1.55	0.83	0.35	
Diaphragmatic hernia	2.64	2.31	2.12	1.83	0.78	1.07	
Omphalocele	1.99	1.34	1.16	0.93	0.63	0.52	
Gastroschisis	0.61	0.40	0.42	0.37	0.38	0.63	
Unspecified Omphalocele / Gastroschisis	0.32	0.40	0.17	0.11	0.04	0.00	
Prune belly sequence	0.49	0.60	0.64	0.32	0.11	0.23	
Trisomy 13	0.32	0.47	0.37	0.60	0.36	0.29	
Trisomy 18	0.77	1.17	1.08	0.69	0.66	0.65	
Down syndrome, all ages (include age unknown)	14.34	15.66	12.82	11.27	8.51	7.08	
<20	6.86	7.68	10.76	1.23	2.22	5.92	
20-24	7.37	6.13	4.97	4.52	5.32	5.17	
25-29	6.17	8.22	7.28	6.34	5.15	3.80	
30-34	10.16	14.16	14.88	11.22	7.60	5.70	
35-39	46.30	45.10	35.93	28.06	13.68	11.13	
40-44	146.04	180.66	72.78	59.45	46.88	29.75	
45+	126.94	284.28	239.04	368.10*	143.54	57.58	
unknown	---	---	---	---	---	---	

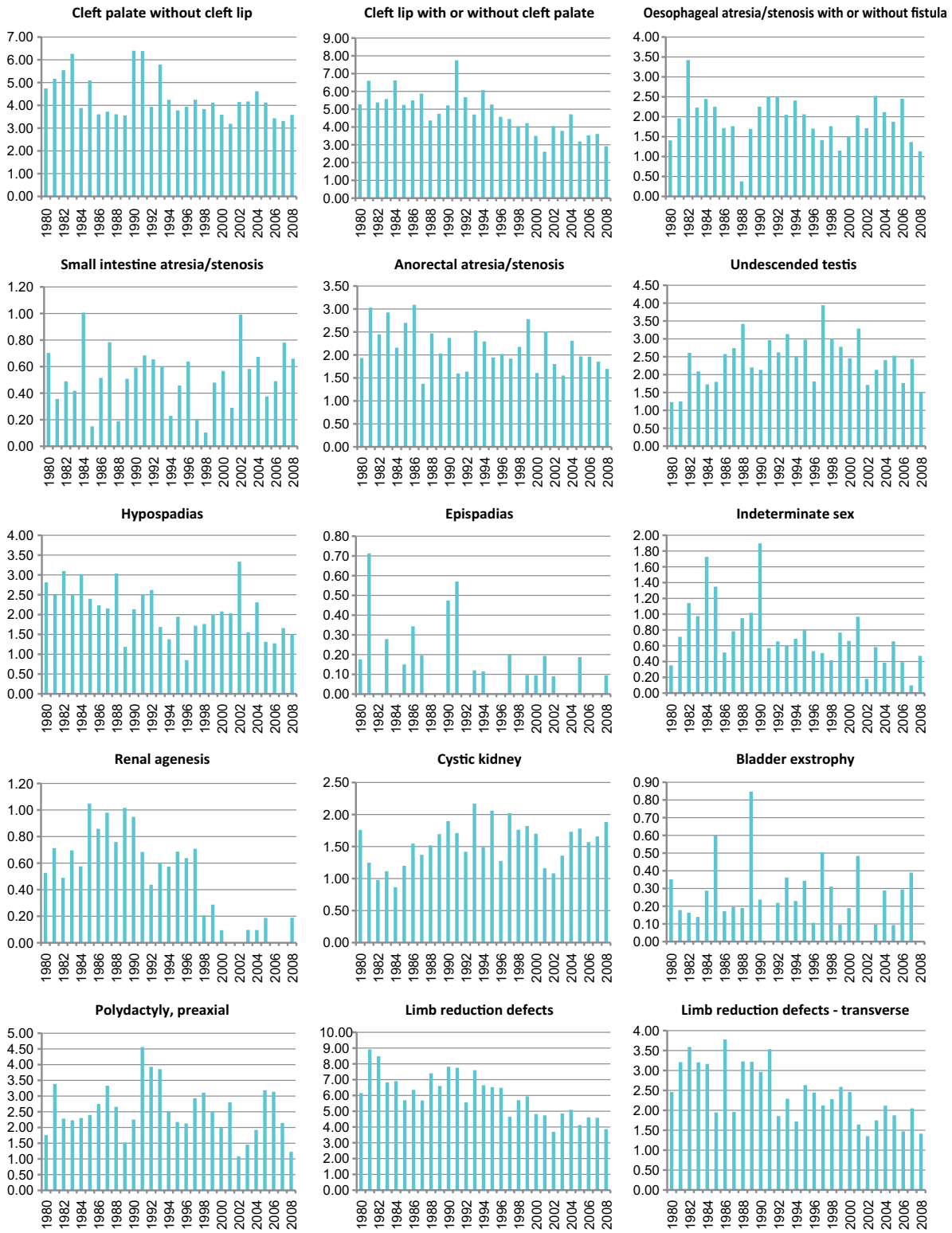
nr = not reported
* data include less than 5 years

Spain: ECEMC

Time trends 1980-2008 (Birth prevalence rates per 10,000)

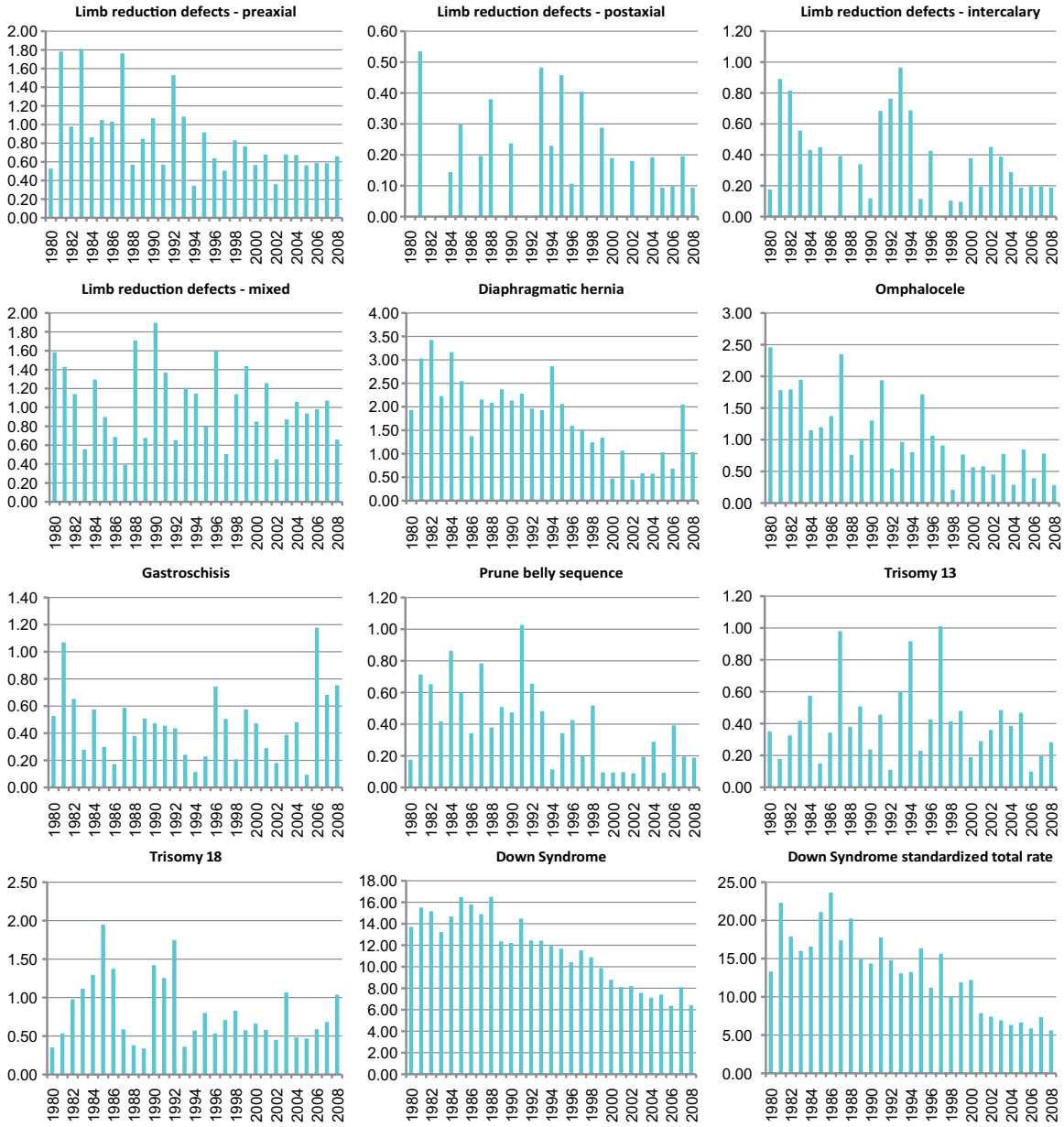
Note: L+S rates

Spain: ECEMC



Note: L+S rates

Spain: ECEMC



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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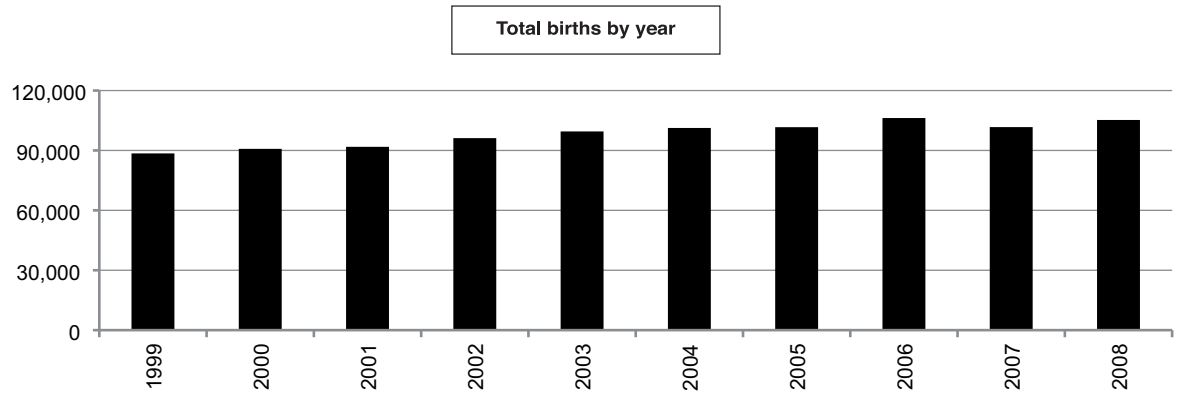
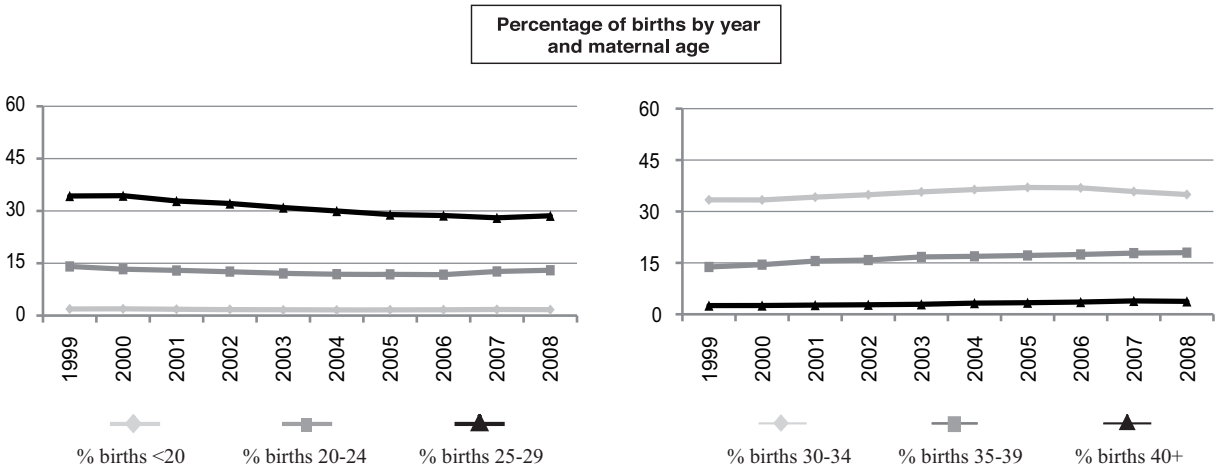
Sweden





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	102	91.9	Cystic kidney	36	33.6
Spina bifida	88	60.7	Limb reduction defects	34	22.4
Encephalocele	34	82.9	Diaphragmatic hernia	54	51.9
Holoprosencephaly	19	73.1	Omphalocele	45	73.8
Hydrocephaly	77	72.0	Gastroschisis	12	23.1
Hypoplastic left heart syndrome	44	58.7	Trisomy 13	73	75.3
Cleft palate without cleft lip	8	4.5	Trisomy 18	206	78.6
Cleft lip with or without cleft palate	11	5.1	Down syndrome	451	51.5
Renal agenesis	37	60.7			

Total ToPs with births defects = 1,562 (Ratio ToPs/Births: 4.99 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Sweden, 2008

Live births (LB)	104,902
Stillbirths (SB)	359
Total births	105,261
Number of terminations of pregnancy (ToP) for birth defects	545

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	35	3.52
Spina bifida	23	0	28	4.85
Encephalocele	3	0	12	1.43
Microcephaly	5	0	1	0.57
Holoprosencephaly	3	0	5	0.76
Hydrocephaly	11	0	17	2.66
Anophthalmos	3	0	1	0.38
Microphthalmos	1	0	1	0.19
Unspecified Anophthalmos/Microphthalmos	2	0	0	0.19
Anotia	2	0	0	0.19
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	2	0	0	0.19
Transposition of great vessels	42	1	1	4.18
Tetralogy of Fallot	23	0	0	2.19
Hypoplastic left heart syndrome	13	0	17	2.85
Coarctation of aorta	44	0	2	4.37
Choanal atresia, bilateral	4	0	0	0.38
Cleft palate without cleft lip	57	0	1	5.51
Cleft lip with or without cleft palate	90	0	2	8.74
Oesophageal atresia/stenosis with or without fistula	28	0	3	2.95
Small intestine atresia/stenosis	20	0	1	2.00
Anorectal atresia/stenosis	29	1	9	3.71
Undescended testis (36 weeks of gestation or later)	2	0	0	0.19
Hypospadias	227	0	0	21.57
Epispadias	3	0	1	0.38
Indeterminate sex	1	0	0	0.10
Renal agenesis	7	0	18	2.38
Cystic kidney	20	0	12	3.04
Bladder exstrophy	4	0	0	0.38
Polydactyly, preaxial	10	0	1	1.05
Total Limb reduction defects (include unspecified)	35	1	6	3.99
Transverse	25	1	4	2.85
Preaxial	3	0	2	0.48
Postaxial	2	0	0	0.19
Intercalary	0	0	0	0.00
Mixed	5	0	0	0.48
Unspecified	15	0	6	2.00
Diaphragmatic hernia	18	0	18	3.42
Omphalocele	5	0	14	1.81
Gastroschisis	13	0	4	1.62
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	1	0	3	0.38
Trisomy 13	7	0	31	3.61
Trisomy 18	13	3	52	6.46
Down syndrome, all ages (include age unknown)	133	1	180	29.83
<20	0	0	0	0.00
20-24	3	0	2	3.65
25-29	19	0	3	7.31
30-34	34	1	18	14.41
35-39	43	0	72	60.74
40-44	27	0	67	247.63
45+	3	0	18	1235.29
unknown	3	0	0	---

nr = not reported

Sweden, Previous years rates 1999 - 2008

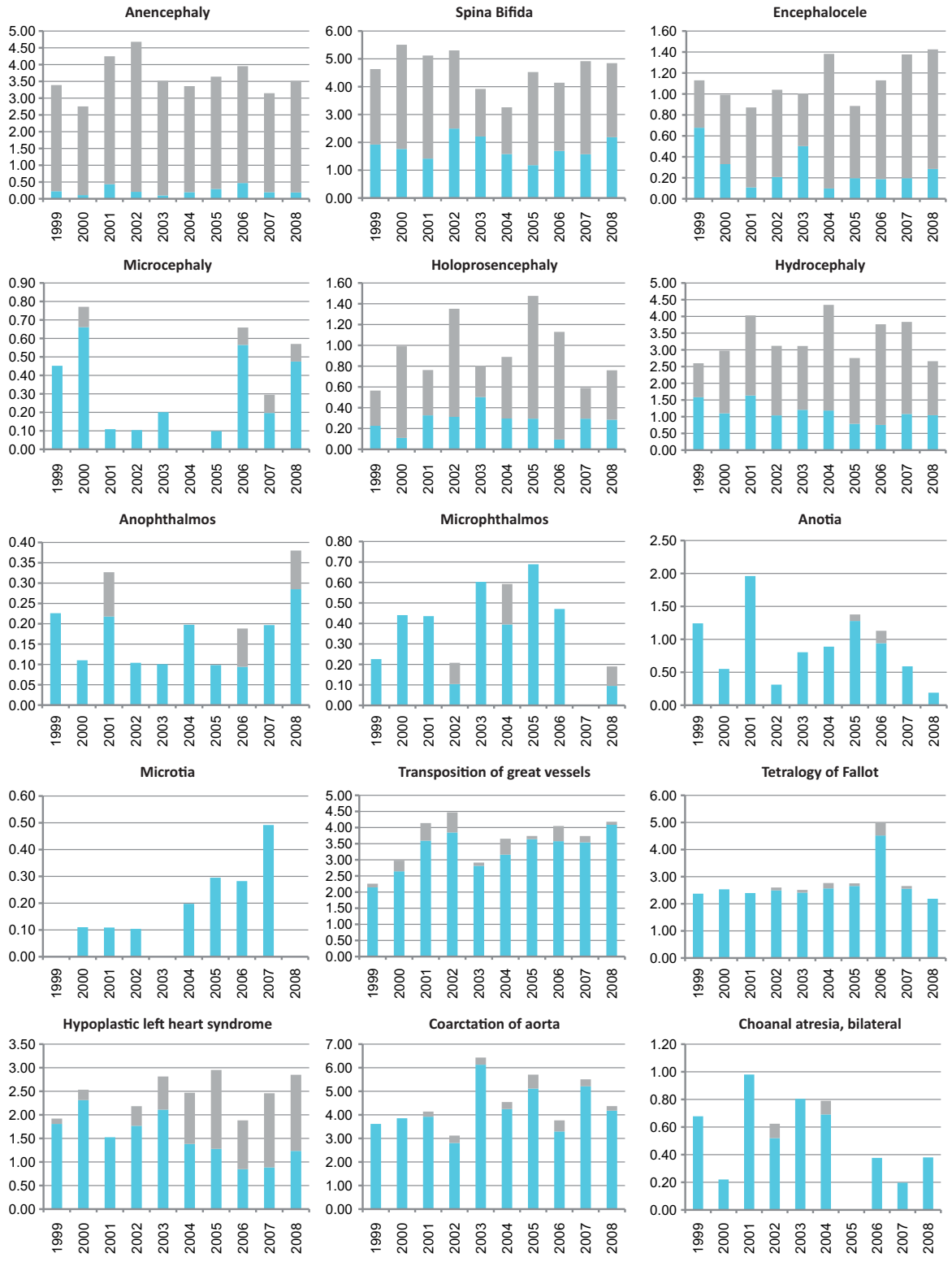
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births						**466,806**	**516,089**
Anencephaly						3.73	3.53
Spina bifida						4.88	4.34
Encephalocele						1.01	1.2
Microcephaly						0.32	0.33
Holoprosencephaly						0.90	0.97
Hydrocephaly						3.17	3.47
Anophthalmos						0.17	0.21
Microphthalmos						0.39	0.39
Unspecified Anophthalmos / Microphthalmos						0.00	0.10*
Anotia						0.96	0.83
Microtia						0.06	0.25
Unspecified Anotia / Microtia						0.00	0.06
Transposition of great vessels						3.36	3.88
Tetralogy of Fallot						2.48	3.08
Hypoplastic left heart syndrome						2.21	2.52
Coarctation of aorta						4.26	4.77
Choanal atresia, bilateral						0.66	0.35
Cleft palate without cleft lip						5.46	5.58
Cleft lip with or without cleft palate						10.05	8.22
Oesophageal atresia / stenosis with or without fistula						2.40	2.48
Small intestine atresia / stenosis						2.25	2.48
Anorectal atresia / stenosis						3.00	2.85
Undescended testis (36 weeks of gestation or later)						nr	0.10*
Hypospadias						20.61	21.33
Epispadias						0.21	0.16
Indeterminate sex						0.26	0.21
Renal agenesis						1.95	1.59
Cystic kidney						3.00	3.68
Bladder exstrophy						0.24	0.31
Polydactyly, preaxial						4.24	3.91
Total Limb reduction defects (include unspecified)						5.06	4.77
Transverse						3.56	3.12
Preaxial						0.24	0.52
Postaxial						0.19	0.12
Intercalary						0.21	0.21
Mixed						0.86	0.45
Unspecified						0.00	1.11*
Diaphragmatic hernia						2.74	3.18
Omphalocele						2.34	2.62
Gastroschisis						2.01	1.61
Unspecified Omphalocele / Gastroschisis						0.00	0.00*
Prune belly sequence						0.09	0.23
Trisomy 13						2.08	3.14
Trisomy 18						5.96	8.00
Down syndrome, all ages (include age unknown)						24.16	27.19
<20						9.54	10.44
20-24						8.09	9.05
25-29						9.19	9.28
30-34						17.09	17.03
35-39						54.68	55.92
40-44						173.40	180.80
45+						400.00	576.41
unknown						---	---

nr = not reported
* data include less than 5 years

Sweden

Time trends 1999-2008 (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.

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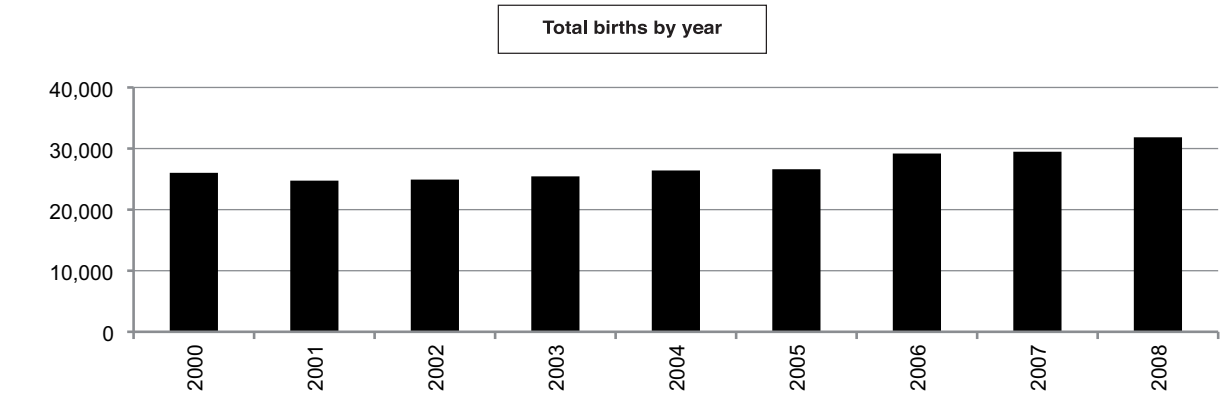
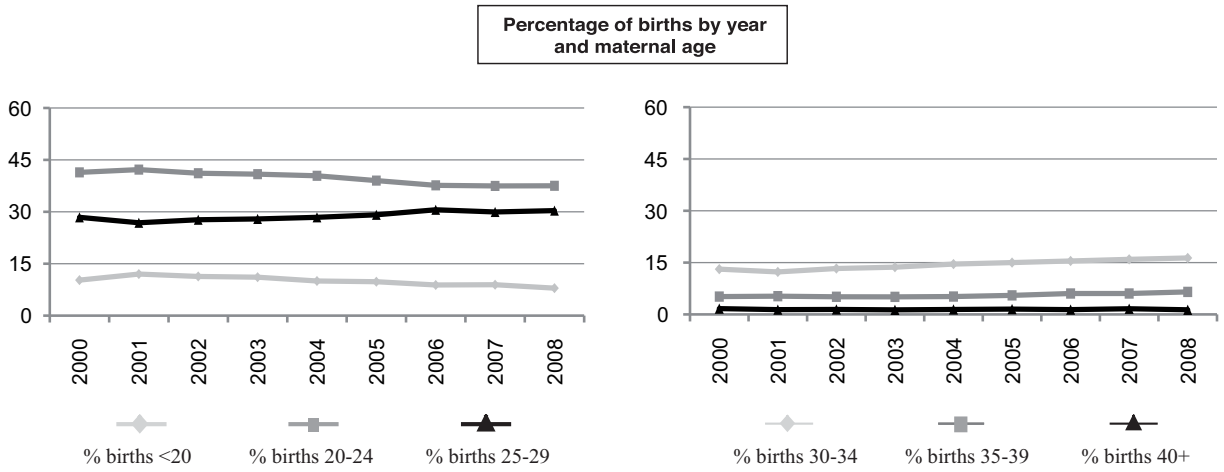
Ukraine: OMNI-Net





Ukraine: OMNI-Net, 2008

Live births (LB)	31,665
Stillbirths (SB)	177
Total births	31,842
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	4	20	7.85
Spina bifida	16	0	17	10.36
Encephalocele	1	0	5	1.88
Microcephaly	18	1	nr	5.97
Holoprosencephaly	2	1	nr	0.94
Hydrocephaly	15	1	nr	5.02
Anophthalmos	0	0	nr	0.00
Microphthalmos	5	1	nr	1.88
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	1	0	nr	0.31
Microtia	7	0	nr	2.20
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	15	0	nr	4.71
Tetralogy of Fallot	8	0	nr	2.51
Hypoplastic left heart syndrome	3	1	nr	1.26
Coarctation of aorta	5	0	nr	1.57
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	21	0	nr	6.60
Cleft lip with or without cleft palate	29	0	nr	9.11
Oesophageal atresia/stenosis with or without fistula	6	0	nr	1.88
Small intestine atresia/stenosis	2	1	nr	0.94
Anorectal atresia/stenosis	8	2	nr	3.14
Undescended testis (36 weeks of gestation or later)	83	0	nr	26.07
Hypospadias	10	0	nr	3.14
Epispadias	0	0	nr	0.00
Indeterminate sex	1	0	nr	0.31
Renal agenesis	2	1	nr	0.94
Cystic kidney	11	2	nr	4.08
Bladder exstrophy	1	0	nr	0.31
Polydactyly, preaxial	17	0	nr	5.34
Total Limb reduction defects (include unspecified)	9	2	nr	3.45
Transverse	3	1	nr	1.26
Preaxial	0	1	nr	0.31
Postaxial	2	0	nr	0.63
Intercalary	1	0	nr	0.31
Mixed	3	0	nr	0.94
Unspecified	0	0	nr	0.00
Diaphragmatic hernia	7	3	nr	3.14
Omphalocele	5	1	nr	1.88
Gastroschisis	3	2	nr	1.57
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13	0	0	nr	0.00
Trisomy 18	1	0	nr	0.31
Down syndrome, all ages (include age unknown)	32	0	nr	10.05
<20	3	0	nr	11.88
20-24	8	0	nr	6.70
25-29	2	0	nr	2.07
30-34	7	0	nr	13.47
35-39	7	0	nr	33.77
40-44	5	0	nr	124.69
45+	0	0	nr	0.00
unknown	0	0	nr	---

nr = not reported

Ukraine: OMNI-Net, Previous years rates 2000 - 2008

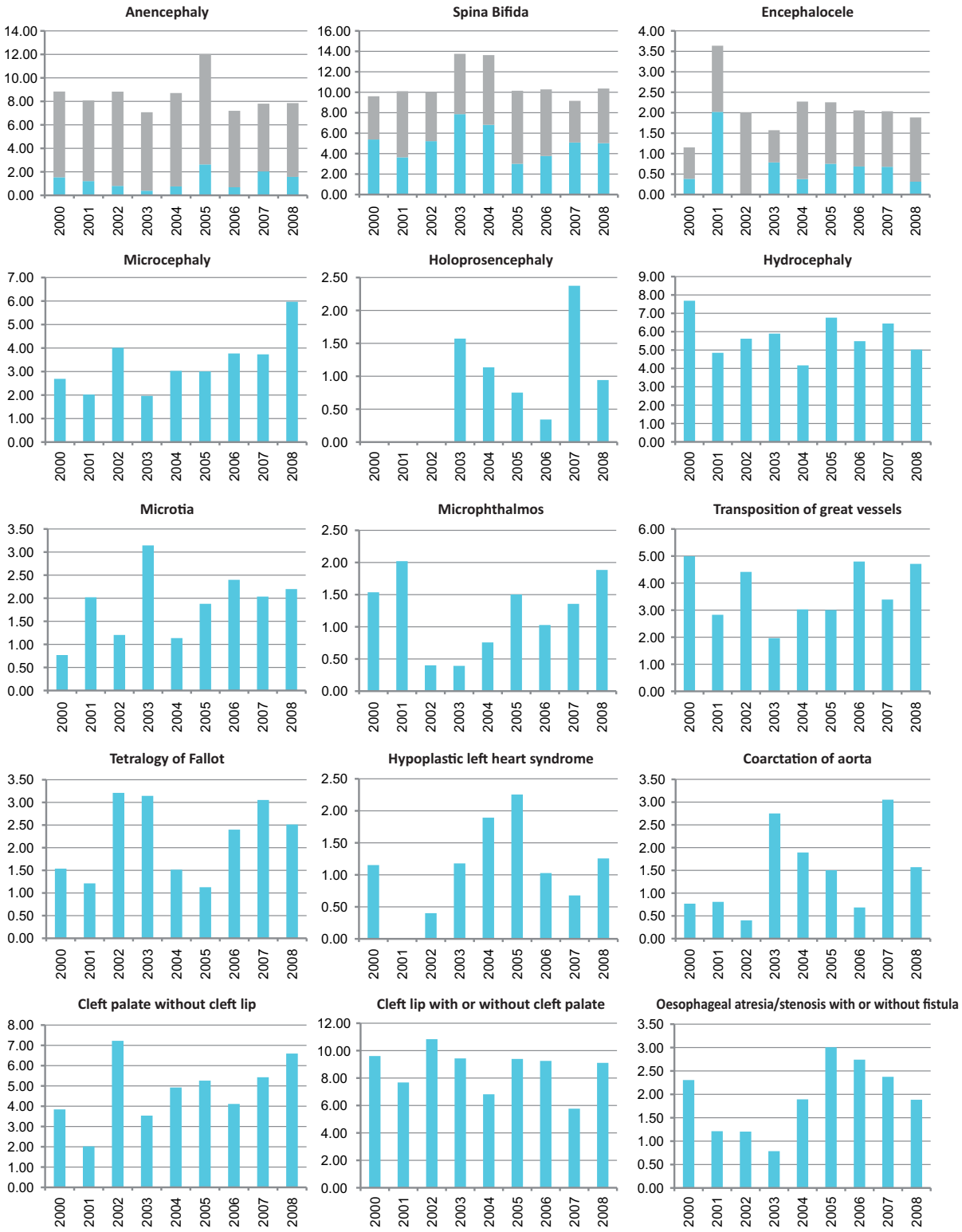
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003*	2004-2008
Total births						**101,137**	**143,530**
Anencephaly						8.21	8.64
Spina bifida						10.88	10.66
Encephalocele						2.08	2.09
Microcephaly						2.67	3.97
Holoprosencephaly						0.40	1.11
Hydrocephaly						6.03	5.57
Anophthalmos						0.10	0.07
Microphthalmos						1.09	1.32
Unspecified Anophthalmos / Microphthalmos						0.00	0.07
Anotia						0.40	0.35
Microtia						1.78	1.95
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						3.56	3.83
Tetralogy of Fallot						2.27	2.16
Hypoplastic left heart syndrome						0.69	1.39
Coarctation of aorta						1.19	1.74
Choanal atresia, bilateral						0.00	0.00
Cleft palate without cleft lip						4.15	5.30
Cleft lip with or without cleft palate						9.39	8.08
Oesophageal atresia / stenosis with or without fistula						1.38	2.37
Small intestine atresia / stenosis						1.48	1.67
Anorectal atresia / stenosis						2.77	2.09
Undescended testis (36 weeks of gestation or later)						39.25	35.95
Hypospadias						3.46	3.14
Epispadias						0.40	0.07
Indeterminate sex						0.69	0.21
Renal agenesis						0.89	0.77
Cystic kidney						1.78	3.55
Bladder exstrophy						0.89	0.56
Polydactyly, preaxial						3.07	4.39
Total Limb reduction defects (include unspecified)						3.76	3.48
Transverse						2.08	1.74
Preaxial						0.49	0.56
Postaxial						0.30	0.35
Intercalary						0.30	0.35
Mixed						0.20	0.49
Unspecified						0.40	0.00
Diaphragmatic hernia						1.68	2.30
Omphalocele						1.29	1.60
Gastroschisis						1.09	1.60
Unspecified Omphalocele / Gastroschisis						0.00	0.00
Prune belly sequence						0.00	0.00
Trisomy 13						0.20	0.35
Trisomy 18						0.30	0.35
Down syndrome, all ages (include age unknown)						12.16	13.31
<20						7.97	12.31
20-24						6.69	7.27
25-29						9.98	8.20
30-34						18.88	14.38
35-39						28.77	40.22
40-44						92.99	142.71
45+						657.89	431.65
unknown						---	---

* data include less than 5 years

Ukraine: OMNI-Net

Time trends 2000-2008 (Birth prevalence rates per 10,000)



Note: L+S rates, ToP rates

Ukraine: OMNI-Net

Note: L+S rates, ToP rates

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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UNITED KINGDOM - WESSEX: WANDA, 2008

Live births (LB)	29,338
Stillbirths (SB)	122
Total births	29,460
Number of terminations of pregnancy (ToP) for birth defects	191

Birth Defects	Number of cases(*)			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	13	4.41
Spina bifida	<5	0	13	nc
Encephalocele	0	0	2	0.68
Microcephaly	nr	nr	nr	nr
Holoprosencephaly	<5	0	<5	nc
Hydrocephaly	8	0	6	4.75
Anophthalmos	nr	nr	nr	nr
Microphthalmos	nr	nr	nr	nr
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	9	0	0	3.05
Tetralogy of Fallot	9	0	<5	nc
Hypoplastic left heart syndrome	7	0	7	4.75
Coarctation of aorta	12	0	<5	nc
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	18	0	<5	nc
Cleft lip with or without cleft palate	33	0	<5	nc
Oesophageal atresia/stenosis with or without fistula	5	0	<5	nc
Small intestine atresia/stenosis	11	0	0	3.73
Anorectal atresia/stenosis	12	0	0	4.07
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	25	0	<5	nc
Epispadias	0	0	0	0.00
Indeterminate sex	5	0	<5	nc
Renal agenesis	<5	0	<5	nc
Cystic kidney	9	0	<5	nc
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	<5	0	<5	nc
Total Limb reduction defects (include unspecified)	0	0	0	0.00
Transverse	6	0	<5	nc
Preaxial	<5	0	0	nc
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	<5	0	<5	nc
Unspecified	0	0	0	0.00
Diaphragmatic hernia	<5	0	<5	nc
Omphalocele	6	0	<5	nc
Gastroschisis	11	0	<5	nc
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	10	3.73
Trisomy 18	<5	<5	15	nc
Down syndrome, all ages (include age unknown)	nr	nr	nr	nr
<20	<5	0	0	nc
20-24	<5	0	0	nc
25-29	<5	0	<5	nc
30-34	9	0	10	23.21
35-39	7	0	21	55.94
40-44	7	<5	11	nc
45+	0	0	<5	nc
unknown				---

nc = not calculable
nr = not reported
(*) According to national guidelines number of cases < 5 should not be explicitly published

USA-Atlanta: MACDP
Metropolitan Atlanta Congenital Defects Program

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

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

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

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

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

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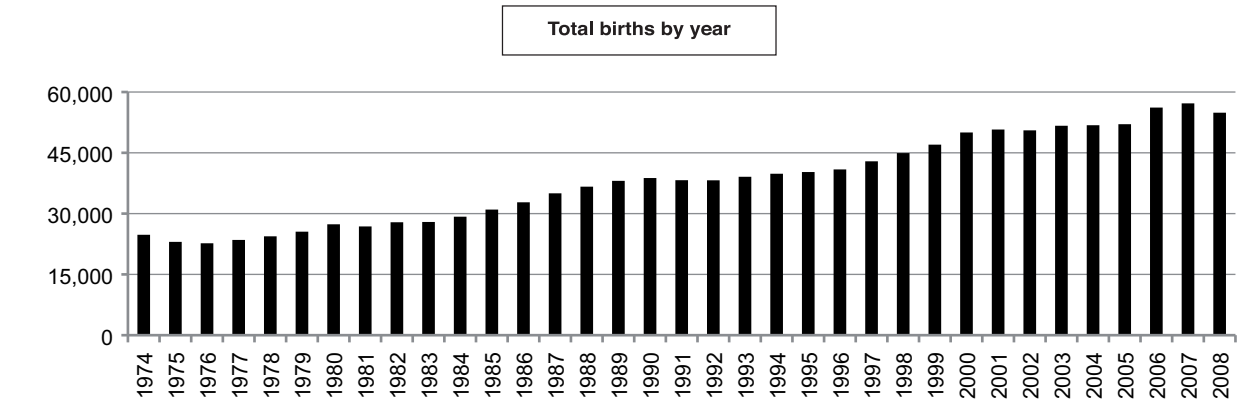
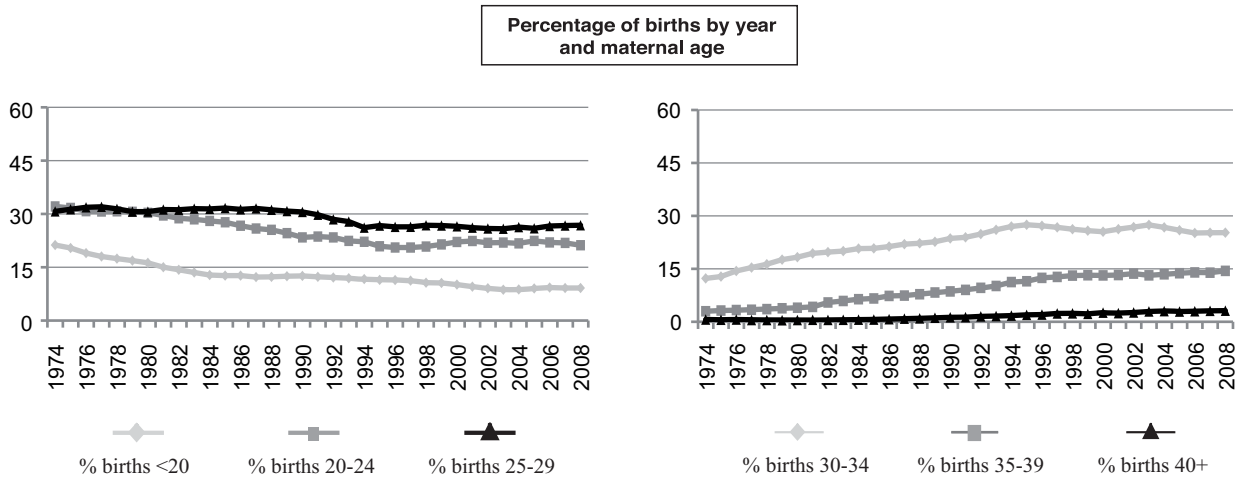
USA-Atlanta: MACDP





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	18	40.0	Cystic kidney	63	64.9
Spina bifida	37	54.4	Limb reduction defects	54	72.0
Encephalocele	9	50.0	Diaphragmatic hernia	23	54.8
Holoprosencephaly	16	61.5	Omphalocele	23	67.6
Hydrocephaly	69	58.5	Gastroschisis	57	67.9
Hypoplastic left heart syndrome	20	69.0	Trisomy 13	10	50.0
Cleft palate without cleft lip	50	67.6	Trisomy 18	28	47.5
Cleft lip with or without cleft palate	99	64.3	Down syndrome	156	59.1
Renal agenesis	12	80.0			

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

USA-Atlanta: MACDP, 2008

Live births (LB)	54,356
Stillbirths (SB)	543
Total births	54,899
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	3	10	3.10
Spina bifida	13	1	6	3.64
Encephalocele	6	0	2	1.46
Microcephaly	26	0	0	4.74
Holoprosencephaly	4	1	0	0.91
Hydrocephaly	33	5	3	7.47
Anophthalmos	1	0	0	0.18
Microphthalmos	5	0	0	0.91
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	6	0	0	1.09
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	19	1	0	3.64
Tetralogy of Fallot	21	0	1	4.01
Hypoplastic left heart syndrome	5	1	0	1.09
Coarctation of aorta	19	0	0	3.46
Choanal atresia, bilateral	2	0	0	0.36
Cleft palate without cleft lip	24	0	0	4.37
Cleft lip with or without cleft palate	44	4	1	8.93
Oesophageal atresia/stenosis with or without fistula	8	0	0	1.46
Small intestine atresia/stenosis	15	0	0	2.73
Anorectal atresia/stenosis	14	0	2	2.91
Undescended testis (36 weeks of gestation or later)	48	0	0	8.74
Hypospadias	33	0	0	6.01
Epispadias	2	0	0	0.36
Indeterminate sex	9	1	1	2.00
Renal agenesis	2	0	0	0.36
Cystic kidney	31	0	5	6.56
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	10	0	0	1.82
Total Limb reduction defects (include unspecified)	15	3	3	3.83
Transverse	7	3	2	2.19
Preaxial	1	0	0	0.18
Postaxial	0	0	0	0.00
Intercalary	2	0	1	0.55
Mixed	4	0	0	0.73
Unspecified	1	0	0	0.18
Diaphragmatic hernia	15	2	1	3.28
Omphalocele	5	2	2	1.64
Gastroschisis	23	1	2	4.74
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	4	0	0	0.73
Trisomy 13	3	1	3	1.28
Trisomy 18	6	2	6	2.55
Down syndrome, all ages (include age unknown)	78	3	10	16.58
<20	4	0	0	7.95
20-24	9	1	0	8.59
25-29	5	0	0	3.40
30-34	24	1	2	19.48
35-39	21	1	6	35.36
40-44	14	0	2	98.34
45+	1	0	0	98.04
unknown	0	0	0	---

nr = not reported

USA-Atlanta: MACDP, Previous years rates 1974 - 2008

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

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births	**118,381**	**135,541**	**164,677**	**192,408**	**208,832**	**249,999**	**272,130**
Anencephaly	4.98	4.50	3.83	2.91	3.64	2.76	2.46
Spina bifida	7.43	6.27	6.50	4.21	5.55	3.52	3.90
Encephalocele	2.11	2.29	2.31	1.14	1.77	1.48	1.14
Microcephaly	4.81	5.98	6.07	4.99	7.90	6.68	5.03
Holoprosencephaly	0.51	0.59	1.46	1.25	1.10	0.80	1.29
Hydrocephaly	9.38	9.37	7.83	5.77	7.09	7.44	7.02
Anophthalmos	0.51	0.59	0.73	0.73	0.34	0.28	0.48
Microphthalmos	3.46	4.43	3.22	2.96	2.97	2.48	1.21
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.25	0.07	0.12	0.26	0.19	0.28	0.11
Microtia	1.44	1.25	1.46	1.46	1.25	1.52	1.10
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	4.90	5.31	5.65	4.57	5.27	5.68	4.30
Tetralogy of Fallot	2.53	3.69	4.13	3.95	4.31	4.32	3.78
Hypoplastic left heart syndrome	2.37	2.80	2.19	2.96	3.06	2.68	1.76
Coarctation of aorta	3.80	4.35	4.37	4.57	4.88	5.72	4.92
Choanal atresia, bilateral	0.42	0.15	0.43	0.16	0.53	0.44	0.37
Cleft palate without cleft lip	7.52	4.50	5.22	5.09	5.03	6.28	4.96
Cleft lip with or without cleft palate	11.23	11.88	9.53	9.10	9.67	7.96	9.77
Oesophageal atresia / stenosis with or without fistula	2.45	2.43	2.31	2.29	2.06	2.04	1.91
Small intestine atresia / stenosis	1.77	1.55	1.58	1.66	1.58	2.08	2.06
Anorectal atresia / stenosis	4.81	3.62	4.07	3.79	3.74	3.16	3.31
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	8.88*	20.12	11.72
Hypospadias	1.18	1.11	4.62	4.57	6.70	9.40	6.06
Epispadias	1.01	1.03	0.55	0.73	0.34	0.44	0.55
Indeterminate sex	2.20	2.14	1.21	1.20	1.29	1.52	1.58
Renal agenesis	1.86	1.92	1.58	1.30	1.39	0.92	0.85
Cystic kidney	2.37	2.58	4.01	4.94	5.46	6.44	5.77
Bladder exstrophy	0.51	0.30	0.18	0.31	0.19	0.12	0.04
Polydactyly, preaxial	1.77	1.99	2.67	2.75	3.02	2.20	2.20
Total Limb reduction defects (include unspecified)	6.50	4.50	4.49	4.78	6.46	5.80	3.90
Transverse	3.97	2.80	2.98	3.43	3.59	3.28	1.98
Preaxial	1.18	0.74	0.61	0.78	1.10	1.24	0.44
Postaxial	0.17	0.30	0.30	0.21	0.38	0.16	0.33
Intercalary	0.59	0.30	0.30	0.10	0.29	0.16	0.33
Mixed	0.08	0.37	0.24	0.16	0.77	0.76	0.66
Unspecified	0.51	0.00	0.06	0.10	0.34	0.16	0.15
Diaphragmatic hernia	2.87	2.07	2.73	2.60	2.01	2.92	2.61
Omphalocele	4.05	3.47	2.61	2.65	2.78	2.12	1.95
Gastroschisis	1.44	2.21	2.13	2.65	2.01	2.64	4.37
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.05	0.00	0.00	0.00
Prune belly sequence	0.68	0.59	0.49	0.31	0.24	0.44	0.51
Trisomy 13	1.01	1.18	1.82	1.25	1.72	1.88	1.43
Trisomy 18	0.59	1.48	2.31	2.29	3.88	4.88	3.56
Down syndrome, all ages (include age unknown)	8.45	11.36	9.47	11.43	17.62	17.92	16.46
<20	nr	8.01*	5.83	7.20	10.20	6.26	8.49
20-24	nr	7.45*	7.97	6.42	8.90	7.47	7.07
25-29	nr	8.17*	6.38	7.76	7.96	8.24	6.80
30-34	nr	17.83*	11.61	11.37	14.24	14.56	14.62
35-39	nr	22.25*	22.08	23.32	46.24	49.73	37.25
40-44	nr	103.99*	48.23	62.16	136.60	110.64	114.00
45+	nr	0.00*	0.00	547.95	59.52	262.30	87.34
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

USA-Atlanta: MACDP

Time trends 1974-2008 (Birth prevalence rates per 10,000)

Note: L+S rates, ToP rates

USA-Atlanta: MACDP

Note: L+S rates, ToP rates

USA-Atlanta: MACDP

Note: L+S rates, ToP rates

USA-Texas: BDES

Texas Birth Defects Epidemiology and Surveillance Branch

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

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

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

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

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

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

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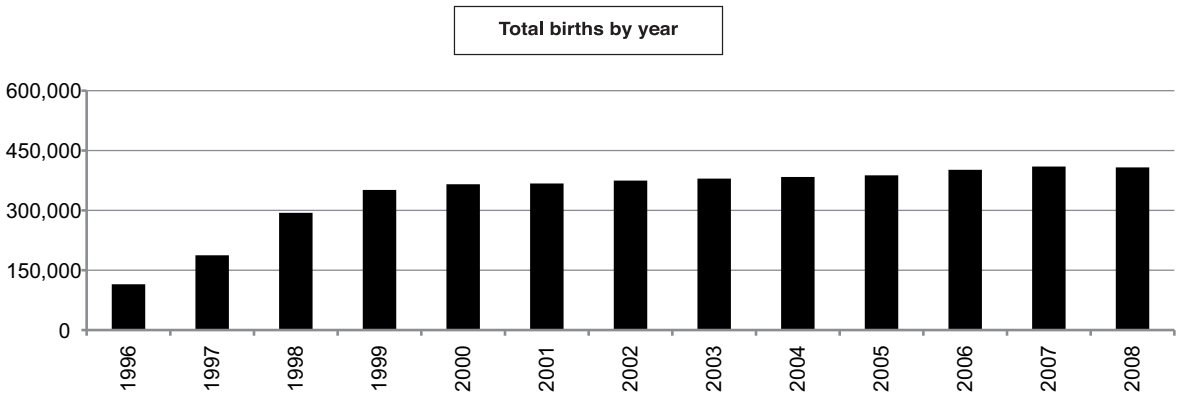
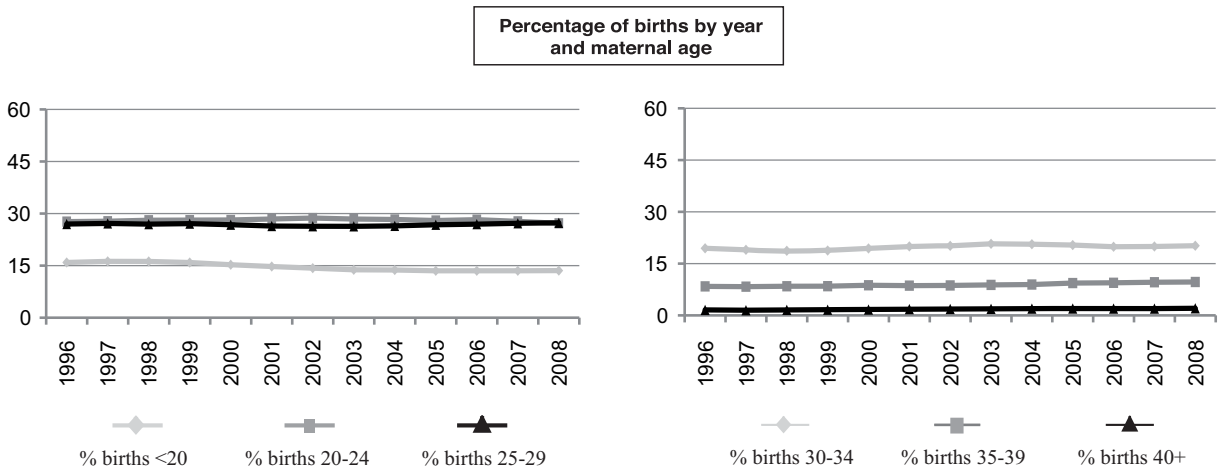
Website: http://www.dshs.state.tx.us/birthdefects/

USA-Texas: BDES





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	98	32.7	Cystic kidney	18	2.5
Spina bifida	21	4.8	Limb reduction defects	30	4.3
Encephalocele	19	15.0	Diaphragmatic hernia	6	1.5
Holoprosencephaly	21	11.2	Omphalocele	20	7.9
Hydrocephaly	37	4.1	Gastroschisis	13	1.8
Hypoplastic left heart syndrome	3	1.1	Trisomy 13	24	15.8
Cleft palate without cleft lip	6	0.8	Trisomy 18	70	19.5
Cleft lip with or without cleft palate	37	2.8	Down syndrome	58	3.3
Renal agenesis	28	9.3			

Total ToPs with births defects = 567 (Ratio ToPs/Births: 0.46 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Texas: BDES, 2008

Live births (LB)	405,242
Stillbirths (SB)	2,474
Total births	407,716
Number of terminations of pregnancy (ToP) for birth defects	183

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	56	21	32	2.67
Spina bifida	134	5	4	3.51
Encephalocele	31	6	4	1.01
Microcephaly	447	6	0	11.11
Holoprosencephaly	34	4	2	0.98
Hydrocephaly	264	5	7	6.77
Anophthalmos	7	1	1	0.22
Microphthalmos	115	2	1	2.89
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	12	3	1	0.39
Microtia	146	0	2	3.63
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	217	2	0	5.37
Tetralogy of Fallot	177	1	0	4.37
Hypoplastic left heart syndrome	86	1	0	2.13
Coarctation of aorta	206	2	0	5.10
Choanal atresia, bilateral	53	1	0	1.32
Cleft palate without cleft lip	237	9	4	6.13
Cleft lip with or without cleft palate	403	15	13	10.57
Oesophageal atresia/stenosis with or without fistula	77	1	0	1.91
Small intestine atresia/stenosis	82	0	0	2.01
Anorectal atresia/stenosis	180	13	6	4.88
Undescended testis (36 weeks of gestation or later)	503	5	0	12.46
Hypospadias	650	0	0	15.94
Epispadias	37	0	0	0.91
Indeterminate sex	18	11	3	0.78
Renal agenesis	74	3	6	2.04
Cystic kidney	244	5	5	6.23
Bladder exstrophy	8	0	0	0.20
Polydactyly, preaxial	150	3	1	3.78
Total Limb reduction defects (include unspecified)	197	19	10	5.54
Transverse	93	10	8	2.72
Preaxial	53	5	1	1.45
Postaxial	10	0	0	0.25
Intercalary	8	1	1	0.25
Mixed	27	2	0	0.71
Unspecified	6	1	0	0.17
Diaphragmatic hernia	112	2	2	2.85
Omphalocele	65	9	5	1.94
Gastroschisis	230	14	6	6.13
Unspecified Omphalocele/Gastroschisis	13	6	1	0.49
Prune belly sequence	12	3	1	0.39
Trisomy 13	30	8	7	1.10
Trisomy 18	78	24	18	2.94
Down syndrome, all ages (include age unknown)	500	19	17	13.15
<20	40	2	0	75.98
20-24	83	1	1	76.73
25-29	72	3	4	70.93
30-34	100	4	3	130.11
35-39	126	5	6	347.57
40-44	72	3	3	990.85
45+	7	1	0	1626.02
unknown	0	0	0	---

USA-Texas: BDES, Previous years rates 1996 - 2008

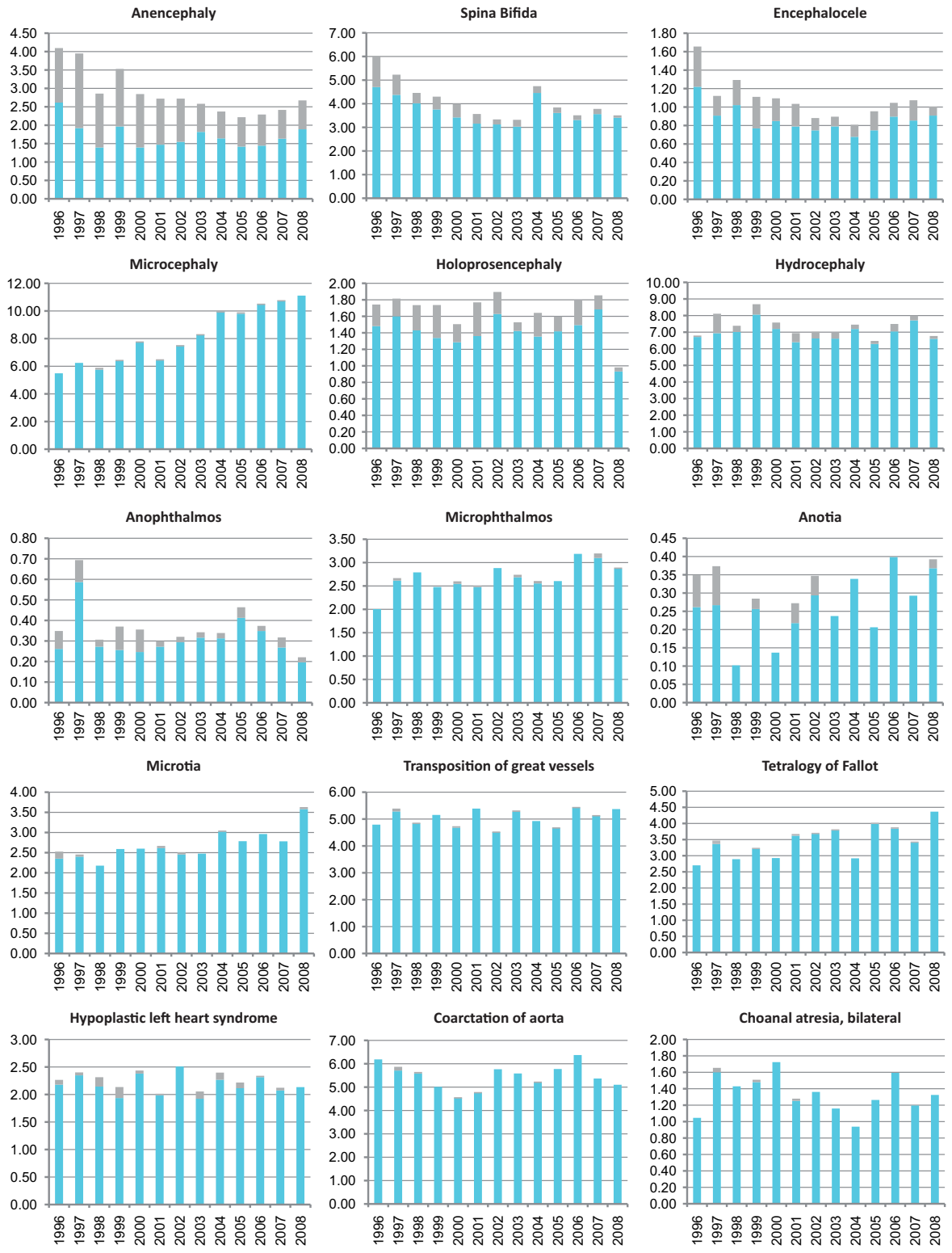
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998*	1999-2003	2004-2008
Total births					**596,012**	**1,838,414**	**1,990,857**
Anencephaly					3.44	2.87	2.40
Spina bifida					5.00	3.69	3.87
Encephalocele					1.31	1.00	0.98
Microcephaly					5.92	7.34	10.47
Holoprosencephaly					1.76	1.69	1.57
Hydrocephaly					7.50	7.42	7.24
Anophthalmos					0.44	0.34	0.34
Microphthalmos					2.60	2.64	2.90
Unspecified Anophthalmos / Microphthalmos					0.00	0.00	0.00
Anotia					0.23	0.26	0.33
Microtia					2.33	2.57	3.04
Unspecified Anotia / Microtia					0.00	0.00	0.00
Transposition of great vessels					5.02	5.03	5.12
Tetralogy of Fallot					3.04	3.48	3.73
Hypoplastic left heart syndrome					2.33	2.23	2.24
Coarctation of aorta					5.82	5.15	5.57
Choanal atresia, bilateral					1.43	1.40	1.27
Cleft palate without cleft lip					5.92	5.75	5.84
Cleft lip with or without cleft palate					11.24	10.49	10.98
Oesophageal atresia / stenosis with or without fistula					2.40	2.20	2.05
Small intestine atresia / stenosis					1.88	1.70	1.95
Anorectal atresia / stenosis					4.16	4.97	4.98
Undescended testis (36 weeks of gestation or later)					7.16	8.84	11.92
Hypospadias					17.60	18.09	16.39
Epispadias					0.64	0.80	0.93
Indeterminate sex					1.61	1.23	0.76
Renal agenesis					2.37	2.26	2.36
Cystic kidney					4.60	4.99	5.96
Bladder exstrophy					0.23	0.24	0.18
Polydactyly, preaxial					2.89	3.20	3.65
Total Limb reduction defects (include unspecified)					5.59	5.54	5.58
Transverse					2.57	2.73	2.91
Preaxial					1.16	1.11	1.25
Postaxial					0.25	0.26	0.23
Intercalary					0.13	0.13	0.17
Mixed					1.26	1.08	0.85
Unspecified					0.22	0.23	0.18
Diaphragmatic hernia					2.42	2.94	3.04
Omphalocele					2.42	2.33	2.12
Gastroschisis					3.71	4.19	5.49
Unspecified Omphalocele / Gastroschisis					0.59	0.53	0.49
Prune belly sequence					0.23	0.34	0.35
Trisomy 13					1.34	1.33	1.20
Trisomy 18					2.73	2.45	2.90
Down syndrome, all ages (include age unknown)					12.89	13.65	14.19
<20					7.37	7.99	7.89
20-24					7.58	7.38	7.44
25-29					6.40	8.17	7.72
30-34					14.18	12.68	14.45
35-39					39.39	38.69	38.88
40-44					117.97	127.43	117.71
45+					141.24	217.97	171.93
unknown					---	---	---

* data include less than 5 years

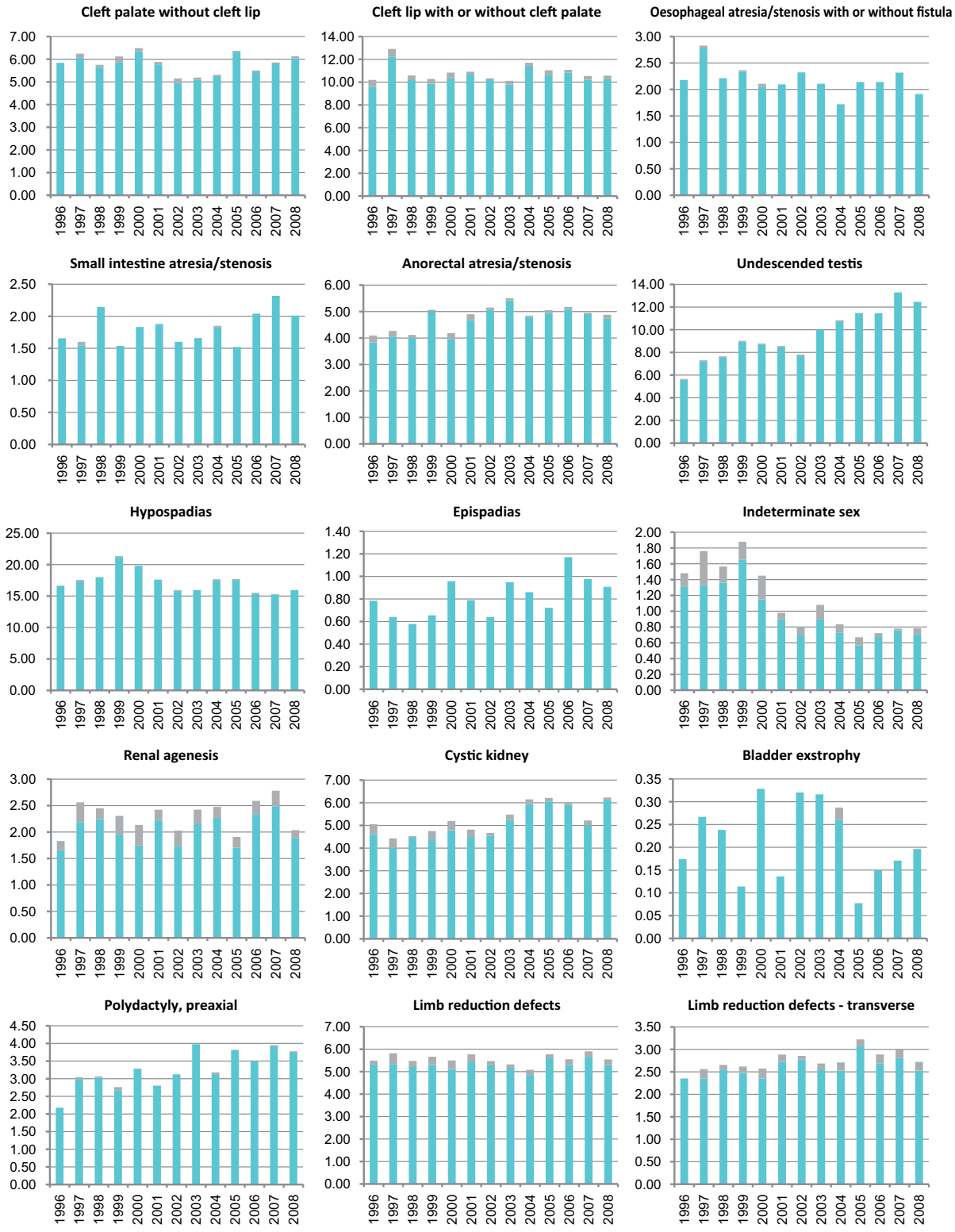
USA-Texas: BDES

Time trends 1996-2007 (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 state wide population based surveillance system covering approximately 50,000 births annually. Stillbirths and terminations of at least 20 weeks gestations are included. Terminations less than 20 weeks are included for all major birth defects. Currently a pilot is ongoing to incorporate metabolic disorders (identified by newborn screening) into surveillance

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. Starting in 2007 all surveillance activities of the UBDN will be funded with State General Funds. The UBDN has additional projects being funded from several sources and includes Maternal Child Health and CDC grants.

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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Phone: 801 584 8573
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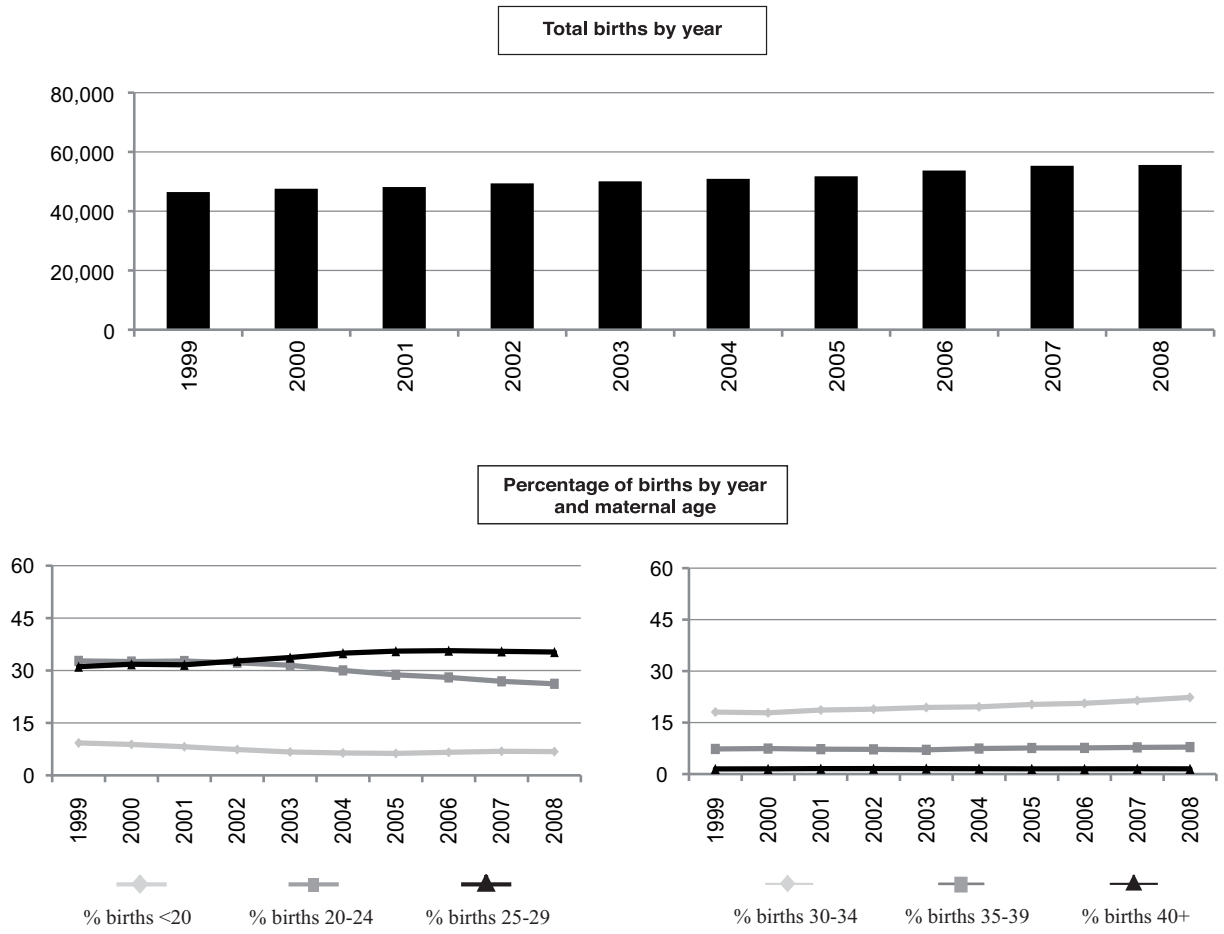
E-mail: mpalmer@utah.gov

Website: http://www.health.utah.gov/birthdefect/)

USA-Utah: UBDN



Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	18	43.9	Cystic kidney	5	7.4
Spina bifida	7	9.5	Limb reduction defects	10	14.9
Encephalocele	4	26.7	Diaphragmatic hernia	1	1.8
Holoprosencephaly	14	35.9	Omphalocele	11	22.9
Hydrocephaly	7	10.4	Gastroschisis	1	1.1
Hypoplastic left heart syndrome	2	3.6	Trisomy 13	10	27.8
Cleft palate without cleft lip	3	2.7	Trisomy 18	19	31.1
Cleft lip with or without cleft palate	13	6.0	Down syndrome	19	8.3
Renal agenesis	5	9.4			

Total ToPs with births defects = 130 (Ratio ToPs/Births: 0.79 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Utah: UBDN, 2008

Live births (LB)	55,605
Stillbirths (SB)	310
Total births	55,915
Number of terminations of pregnancy (ToP) for birth defects	56

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	8	4	2.68
Spina bifida	19	2	3	4.29
Encephalocele	4	0	3	1.25
Microcephaly	19	0	0	3.40
Holoprosencephaly	10	1	4	2.68
Hydrocephaly	16	2	2	3.58
Anophthalmos	2	1	1	0.72
Microphthalmos	12	2	1	2.68
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	21	0	0	3.76
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	20	0	0	3.58
Tetralogy of Fallot	17	1	0	3.22
Hypoplastic left heart syndrome	19	1	0	3.58
Coarctation of aorta	54	0	2	10.02
Choanal atresia, bilateral	2	0	0	0.36
Cleft palate without cleft lip	29	0	1	5.37
Cleft lip with or without cleft palate	67	3	4	13.23
Oesophageal atresia/stenosis with or without fistula	12	1	2	2.68
Small intestine atresia/stenosis	6	0	0	1.07
Anorectal atresia/stenosis	13	0	4	3.04
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	59	0	0	10.55
Epispadias	0	0	0	0.00
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	11	0	1	2.15
Cystic kidney	18	1	1	3.58
Bladder exstrophy	2	0	0	0.36
Polydactyly, preaxial	nr	nr	nr	nr
Total Limb reduction defects (include unspecified)	34	1	5	7.15
Transverse	13	1	1	2.68
Preaxial	10	0	3	2.32
Postaxial	3	0	0	0.54
Intercalary	1	0	0	0.18
Mixed	4	0	0	0.72
Unspecified	3	0	1	0.72
Diaphragmatic hernia	20	2	1	4.11
Omphalocele	15	2	3	3.58
Gastroschisis	35	1	0	6.44
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	7	0	1	1.43
Trisomy 18	6	6	9	3.76
Down syndrome, all ages (include age unknown)	63	6	6	13.41
<20	1	0	0	2.63
20-24	9	2	0	7.52
25-29	12	0	0	6.09
30-34	15	1	1	13.61
35-39	16	1	2	43.16
40-44	10	2	3	187.27
45+	0	0	0	0.00
unknown	0	0	0	---

nr = not reported

USA-Utah: UBDN, Previous years rates 1999 - 2008

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

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998	1999-2003	2004-2008
Total births						**241,651**	**267,340**
Anencephaly						2.15	2.43
Spina bifida						3.56	4.60
Encephalocele						0.91	0.86
Microcephaly						4.01	5.35
Holoprosencephaly						1.37	1.87
Hydrocephaly						4.30	4.26
Anophthalmos						0.17	0.45
Microphthalmos						1.66	1.57
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.12	0.15
Microtia						2.11	3.33
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						5.05	4.60
Tetralogy of Fallot						4.14	3.82
Hypoplastic left heart syndrome						3.64	3.52
Coarctation of aorta						7.78	9.24
Choanal atresia, bilateral						0.17	0.26
Cleft palate without cleft lip						7.49	6.85
Cleft lip with or without cleft palate						14.65	12.49
Oesophageal atresia / stenosis with or without fistula						2.69	2.77
Small intestine atresia / stenosis						1.20	1.61
Anorectal atresia / stenosis						3.56	3.25
Undescended testis (36 weeks of gestation or later)						nr	nr
Hypospadias						4.47	8.57
Epispadias						0.21	0.07
Indeterminate sex						nr	nr
Renal agenesis						3.68	3.29
Cystic kidney						5.21	4.83
Bladder exstrophy						0.21	0.15
Polydactyly, preaxial						nr	nr
Total Limb reduction defects (include unspecified)						6.00	5.24
Transverse						3.19	3.40
Preaxial						1.61	1.42
Postaxial						0.08	0.19
Intercalary						0.08	0.19
Mixed						0.87	0.86
Unspecified						0.17	0.22
Diaphragmatic hernia						3.48	3.37
Omphalocele						2.77	2.54
Gastroschisis						4.55	5.50
Unspecified Omphalocele / Gastroschisis						0.00	0.00
Prune belly sequence						0.12	0.15
Trisomy 13						1.70	1.80
Trisomy 18						3.23	3.70
Down syndrome, all ages (include age unknown)						15.77	14.14
<20						10.80	7.94
20-24						8.06	8.70
25-29						9.12	8.66
30-34						15.14	11.65
35-39						53.68	42.50
40-44						147.02	155.80
45+						495.50	216.45
unknown						---	---

nr = not reported

USA-Utah: UBDN

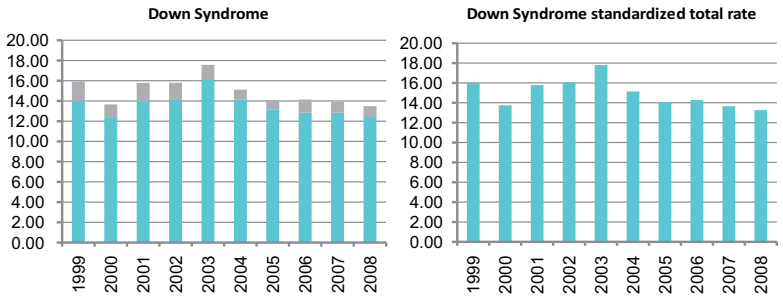
Time trends 1999-2008 (Birth prevalence rates per 10,000)

Note: L+S rates, ToP rates

USA-Utah: UBDN

Note: L+S rates, ToP rates

USA-Utah: UBDN



Note: L+S rates, ToP rates

Wales: CARIS
Congenital Anomaly Register and Information Service

History and Funding:
Data collection commenced on 1st January 1998 and includes any baby where pregnancy ended after this date. CARIS joined EUROCAT in 1998 and ICBDSR in 2004. CARIS is based at Singleton Hospital, Swansea and is funded by the National Assembly for Wales. CARIS aims to collect data which can be used to describe the pattern of congenital anomalies across Wales. This should help:
Build up and monitor the picture of congenital anomalies in Wales
Assess interventions intended to help prevent or detect congenital anomalies
Plan and co-ordinate provision of health services for affected babies and children
Assess possible clusters of birth defects and their causes

Population Coverage:
The Registry covers the entire country of Wales (population-based = All mothers resident in defined geographic area) with an annual number of births of around 32,000.

Sources of Ascertainment:
Reporting is voluntary. The Register relies upon multi-source reporting including: antenatal clinics, delivery units, pediatric departments, ophthalmology, cytogenetics, pathology, orthopaedics, maxillo-facial and regional centres of pediatric surgery. Each delivery unit has a nominated co-ordinator to help ensure good reporting and chase for further details. CARIS staff also visit units to help with data collection. Registration covers all fetuses with prenatally diagnosed anomalies. There is no lower age of cut off, so the fetal losses and early terminations with anomalies are registered. All liveborn babies with structural anomalies are registered if diagnosed before their 1st birthday, but all chromosomal anomalies are registered, even if diagnosed later. Data exchange with the Mersey Register is also important as babies needing specialist services in North Wales are referred to Liverpool.

Termination of Pregnancy:
Termination of pregnancy is legal up to 24 weeks of gestation. Terminations of pregnancy are registered. If congenital anomaly is diagnosed, there is no upper gestational age limit for termination in cases of major anomaly.

Stillbirth Definition and Early Fetal Deaths:
Stillbirth definition: 24 weeks gestation (late fetal death after 23 completed weeks of gestation). Stillbirths of 24 weeks or more gestation are registered. Early fetal deaths/spontaneous abortions have no lower limit for inclusion on the register (earliest recorded go down to 8 weeks gestation). Autopsy rates were not given.

Exposure Data Availability:
xposure information: information on maternal drug use, maternal and paternal diseases and occupations, outcomes of previous pregnancies is available. Folic acid supplementation before and during pregnancy is also collected.

Denominators and Controls Information:
Denominator date is obtained from the Office for National Statistics.

Addresses and Staff:
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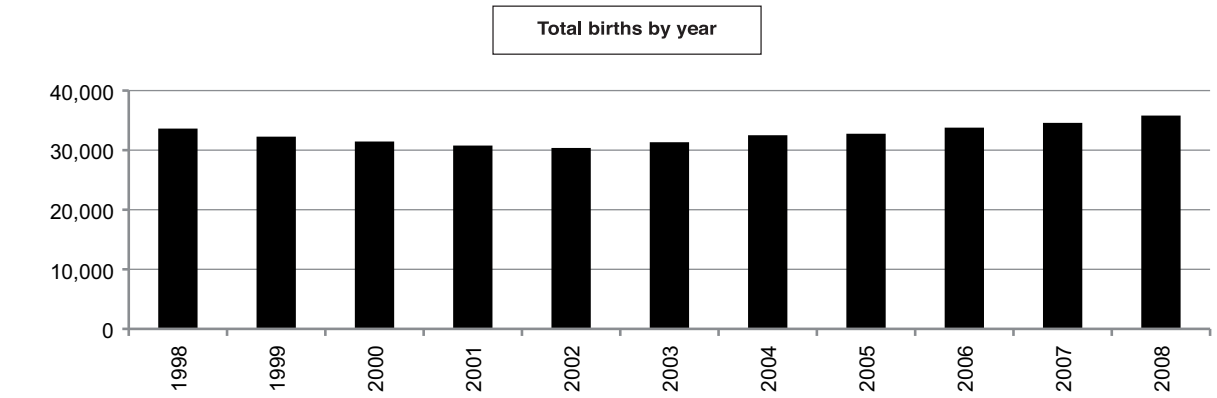
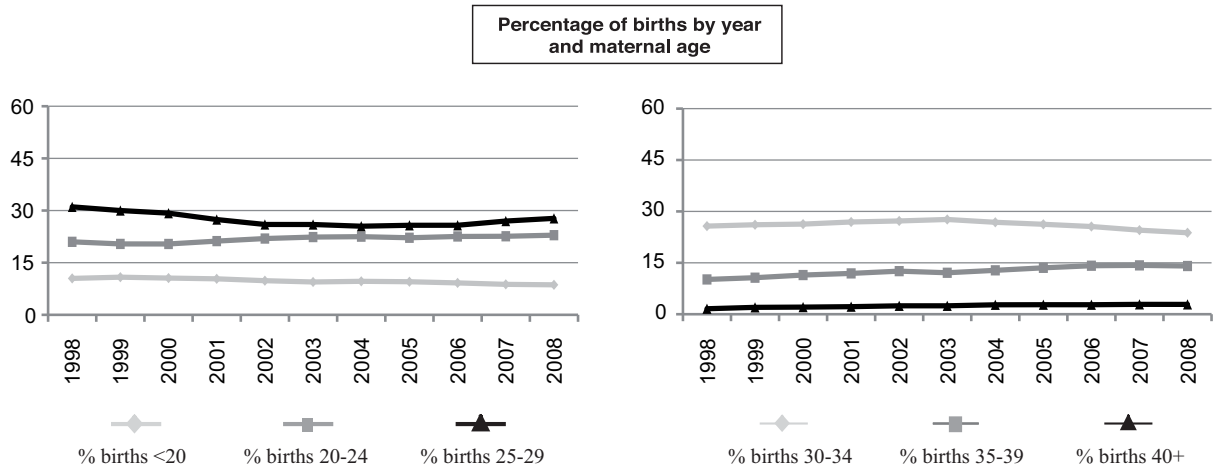
Fax: 44-1792- 285242
E-mail: Margery.Morgan@wales.nhs.uk

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

Wales: CARIS





Terminations of Pregnancy (ToPs) in selected malformations (2006-2008)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	45	97.8	Cystic kidney	21	20.8
Spina bifida	52	74.3	Limb reduction defects	29	29.9
Encephalocele	17	77.3	Diaphragmatic hernia	13	31.7
Holoprosencephaly	12	100.0	Omphalocele	24	60.0
Hydrocephaly	44	48.4	Gastroschisis	4	5.9
Hypoplastic left heart syndrome	15	44.1	Trisomy 13	17	85.0
Cleft palate without cleft lip	11	12.8	Trisomy 18	46	70.8
Cleft lip with or without cleft palate	15	12.7	Down syndrome	110	50.2
Renal agenesis	15	88.2			

Total ToPs with births defects = 537 (Ratio ToPs/Births: 5.16 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Wales: CARIS, 2008

Live births (LB)	35,650
Stillbirths (SB)	165
Total births	35,815
Number of terminations of pregnancy (ToP) for birth defects	170

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP (*)	Total rate
Anencephaly	0	0	18	5.03
Spina bifida	7	0	12	5.31
Encephalocele	2	0	6	2.23
Microcephaly	18	0	0	5.03
Holoprosencephaly	0	0	5	1.40
Hydrocephaly	15	0	13	7.82
Anophthalmos	0	0	0	0.00
Microphthalmos	6	0	0	1.68
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.28
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	0	<5	nc
Tetralogy of Fallot	18	0	0	5.03
Hypoplastic left heart syndrome	8	0	<5	nc
Coarctation of aorta	16	0	<5	nc
Choanal atresia, bilateral	1	0	0	0.28
Cleft palate without cleft lip	20	1	<5	nc
Cleft lip with or without cleft palate	35	0	7	11.73
Oesophageal atresia/stenosis with or without fistula	4	0	<5	nc
Small intestine atresia/stenosis	10	0	0	2.79
Anorectal atresia/stenosis	9	0	6	4.19
Undescended testis (36 weeks of gestation or later)	32	0	<5	nc
Hypospadias	87	0	0	24.29
Epispadias	2	0	0	0.56
Indeterminate sex	1	0	<5	nc
Renal agenesis	1	0	<5	nc
Cystic kidney	25	1	6	8.93
Bladder exstrophy	0	0	<5	nc
Polydactyly, preaxial	4	0	<5	nc
Total Limb reduction defects (include unspecified)	18	0	12	8.38
Transverse	13	0	5	5.03
Preaxial	4	0	<5	nc
Postaxial	0	0	0	0.00
Intercalary	0	0	<5	nc
Mixed	0	0	0	0.00
Unspecified	1	0	0	0.28
Diaphragmatic hernia	9	1	<5	nc
Omphalocele	5	0	6	3.07
Gastroschisis	17	2	<5	nc
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	<5	nc
Trisomy 13	1	0	8	2.51
Trisomy 18	3	3	17	6.42
Down syndrome, all ages (include age unknown)	38	1	25	17.87
<20	2	0	0	6.47
20-24	6	0	<5	nc
25-29	3	0	<5	nc
30-34	11	1	5	19.96
35-39	11	0	12	45.65
40-44	5	0	<5	nc
45+	0	0	<5	nc
unknown	0	0	0	---

nc = not calculable
(*) According to national guidelines number for TOPs < 5 should not be explicitly published

Wales: CARIS, Previous years rates 1998 - 2008

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

	1974-1978	1979-1983	1984-1988	1989-1993	1994-1998*	1999-2003	2004-2008
Total births					**33,620**	**156,185**	**169,422**
Anencephaly					8.63	7.04	5.25
Spina bifida					8.33	8.20	6.73
Encephalocele					1.78	2.37	2.01
Microcephaly					5.35	6.98	5.02
Holoprosencephaly					1.78	1.47	1.36
Hydrocephaly					12.49	9.54	8.79
Anophthalmos					1.19	0.26	0.24
Microphthalmos					2.68	2.11	1.36
Unspecified Anophthalmos / Microphthalmos					0.00	0.00	0.00
Anotia					0.30	0.26	0.53
Microtia					0.59	0.58	0.71
Unspecified Anotia / Microtia					0.00	0.00	0.00
Transposition of great vessels					4.16	5.51	3.60
Tetralogy of Fallot					4.16	2.82	3.84
Hypoplastic left heart syndrome					3.57	3.78	3.13
Coarctation of aorta					8.63	6.08	5.73
Choanal atresia, bilateral					0.00	0.13	0.35
Cleft palate without cleft lip					10.41	9.73	9.09
Cleft lip with or without cleft palate					12.49	9.73	11.33
Oesophageal atresia / stenosis with or without fistula					2.68	3.84	2.54
Small intestine atresia / stenosis					2.38	1.73	2.24
Anorectal atresia / stenosis					5.06	4.67	3.42
Undescended testis (36 weeks of gestation or later)					45.51	8.39	8.15
Hypospadias					26.77	30.67	27.98
Epispadias					0.00	0.64	0.24
Indeterminate sex					0.30	0.51	1.00
Renal agenesis					3.27	2.11	2.07
Cystic kidney					11.01	9.92	9.86
Bladder exstrophy					0.00	0.45	0.24
Polydactyly, preaxial					0.59	1.28	1.00
Total Limb reduction defects (include unspecified)					11.90	10.63	8.50
Transverse					5.95	4.67	4.78
Preaxial					1.49	1.60	1.36
Postaxial					0.59	0.64	0.12
Intercalary					1.49	1.86	1.42
Mixed					0.89	1.15	0.53
Unspecified					1.49	1.34	0.53
Diaphragmatic hernia					2.97	4.03	3.66
Omphalocele					3.87	3.78	4.01
Gastroschisis					5.06	4.99	6.85
Unspecified Omphalocele / Gastroschisis					1.19	0.58	0.18
Prune belly sequence					0.30	0.13	0.12
Trisomy 13					3.27	2.24	2.12
Trisomy 18					4.46	4.35	6.49
Down syndrome, all ages (include age unknown)					19.93	19.46	22.31
<20					11.35	8.15	7.75
20-24					8.50	6.33	8.90
25-29					14.37	10.15	8.72
30-34					15.04	16.70	18.62
35-39					52.75	52.44	58.24
40-44					213.18	162.85	147.22
45+					0.00	340.91	379.15
unknown					---	---	---

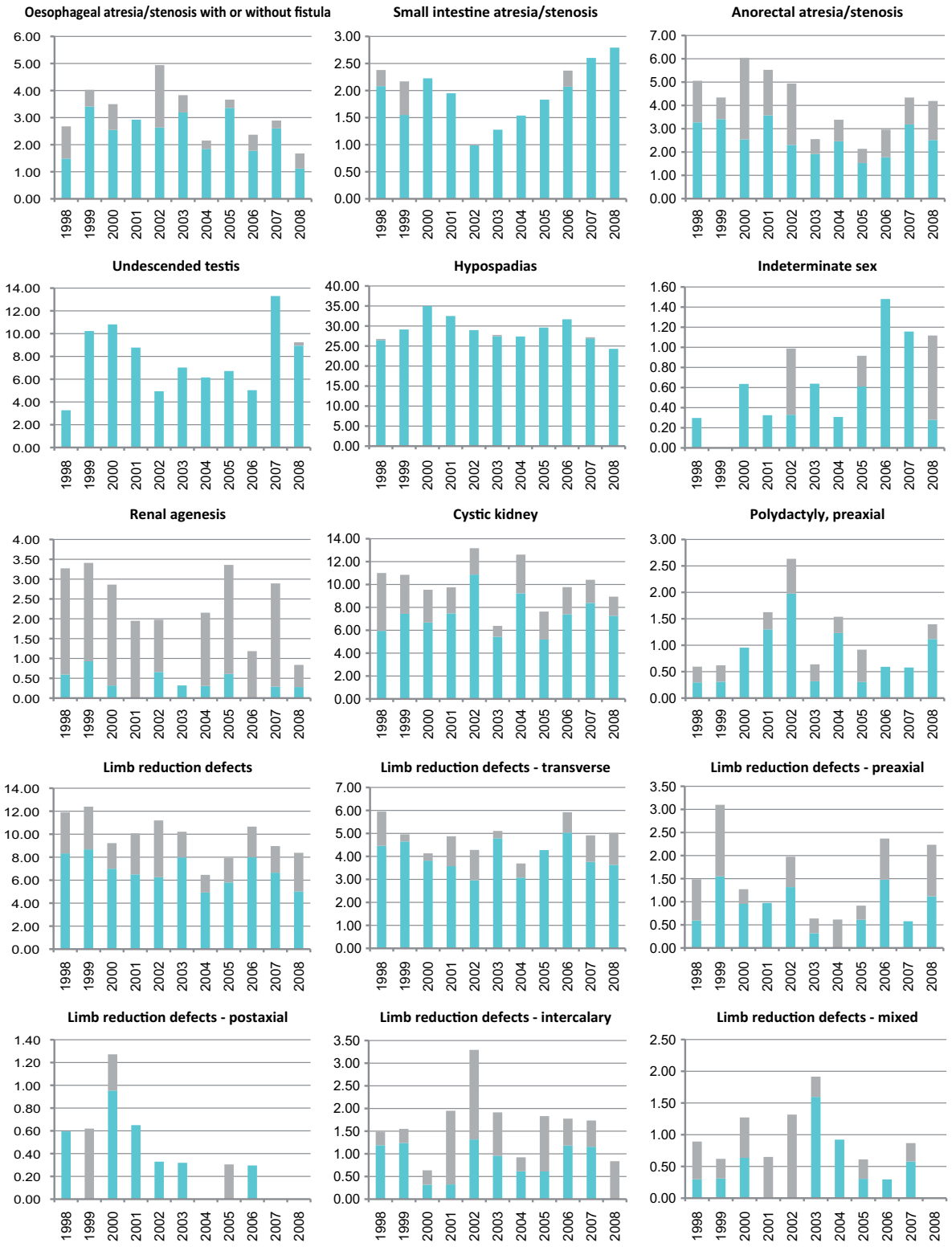
nr = not reported
* data include only 1 year

Wales: CARIS

Time trends 1998-2008 (Birth prevalence rates per 10,000)

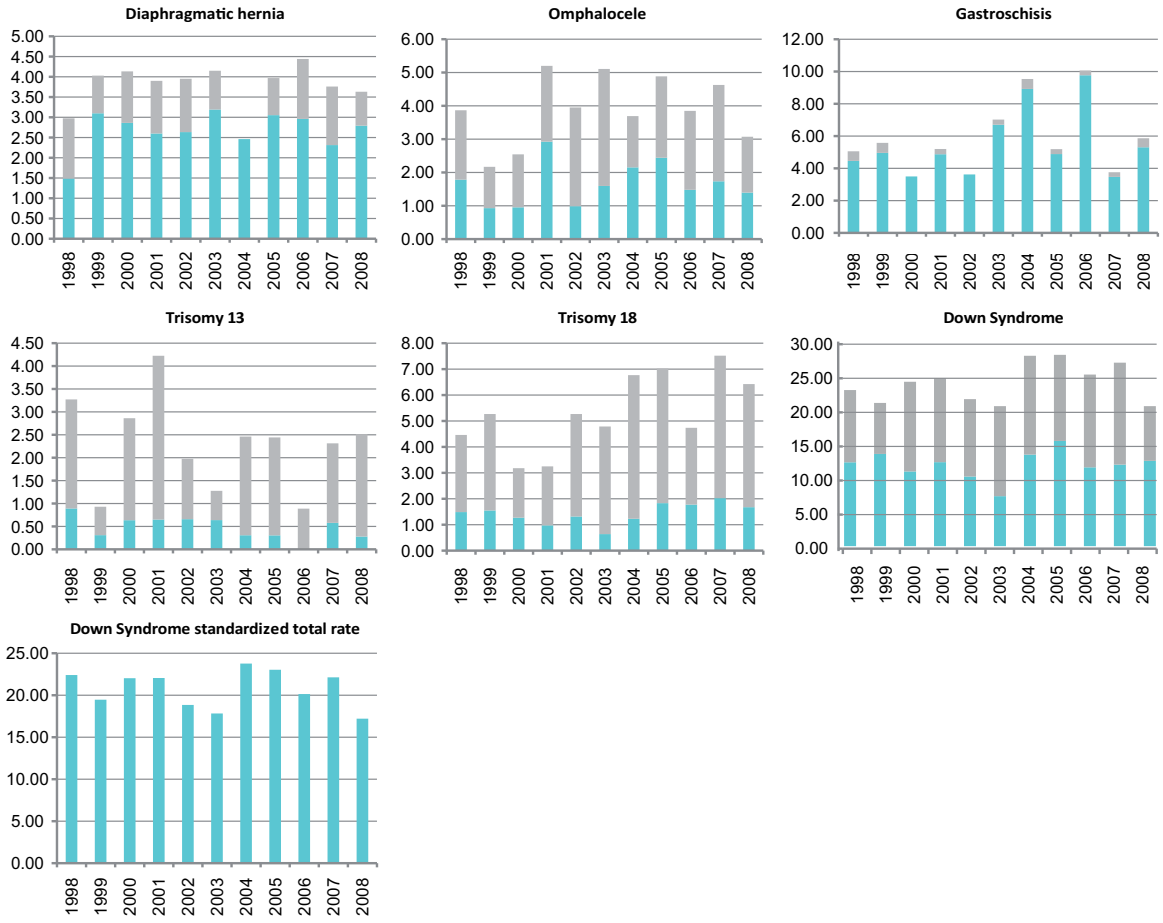
Note: L+S rates, ToP rates

Wales: CARIS



Note: L+S rates, ToP rates

Wales: CARIS



Note: L+S rates, ToP rates

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

France: Strasbourg

Strasbourg Prospective Study 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 Social Security, Ministry of Health, and INSERM.

Sources of ascertainment:
Reports are obtained from pediatricians examining the newborn infants. A control infant is selected for each malformed one: the next infant of the same sex as the proband born at that hospital.

Exposure information:
Detailed information on various exposures is obtained by interview of the mothers of the malformed infants and their controls. The children are followed to the age of one year.

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

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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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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. The Program is an associate member of the Clearinghouse.

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 Monitoring Systems. Collaborative publications, made by two or more ICBDSR members in any context, are first shown and not repeated in the specific registry section. Papers can be obtained contacting authors.

Collaborative Publications

Clementi M, Di Gianantonio E, Cassina M, Leoncini E, Botto LD, Mastroiacovo P; SAFE-Med Study Group. (Castilla EE, Bakker MK, Bianca S, Cocchi G, de Vigan C, Merlob P, Pierini A, Scarano G, Sipek A, Yamanaka M). Treatment of hyperthyroidism in pregnancy and birth defects. J Clin Endocrinol Metab. 2010, 95: E337-E341.

Lisi A, Botto LD, Robert-Gnansia E, Castilla EE, Bakker MK, Bianca S, Cocchi G, de Vigan C, Dutra MG, Horacek J, Merlob P, Pierini A, Scarano G, Sipek A, Yamanaka M, Pierpaolo Mastroiacovo. Surveillance of Adverse Fetal Effects of Medications (SAFE-Med): findings from the International Clearinghouse of Birth Defects Surveillance and Research. Reproductive Toxicology 2010, 29: 433-442.

Leoncini E, Botto LD, Cocchi G, Annerén G, Bower C, Halliday J, Amar E, Bakker MK, Bianca S, Canessa Tapia MA, Castilla EE, Csáky-Szunyogh M, Dastgiri S, Feldkamp ML, Gatt M, Hirahara F, Landau D, Lowry RB, Marengo L, McDonnell R, Mathew TM, Morgan M, Mutchinick OM, Pierini A, Poetzsch S, Ritvanen A, Scarano G, Siffel C, Sípek A, Szabova E, Tagliabue G, Vollset SE, Wertelecki W, Zhuchenko L, Mastroiacovo P. How valid are the rates of Down syndrome internationally? Findings from the International Clearinghouse for Birth Defects Surveillance and Research. Am J Med Genet A. 2010;152A(7):1670-80

Cocchi G, Gualdi S, Bower C, Halliday J, Jonsson B, Myrelid A, Mastroiacovo P, Amar E, Bakker MK, Correa A, Doray B, Melve KK, Koshnood B, Landau D, Mutchinick OM, Pierini A, Ritvanen A, Ruddock V, Scarano G, Sibbald B, Sípek A, Tenconi R, Tucker D, Annerén G. International trends of Down syndrome 1993-2004: Births in relation to maternal age and terminations of pregnancies.Birth Defects Res A Clin Mol Teratol. 2010 88(6):474-9.

Canada, Alberta: ACASS

Lowry RB, Johnson CY, Gagnon F, Little J. Segregation analysis of cleft lip with or without cleft palate in the First Nations (Amerindians) people of British Columbia & review of isolated cleft palate etiologies. Birth Defects Research (Part A) 85:568-573, 2009.

Ferrier RA, Lowry RB, Lemire EG, Stoeber GP, Howard J, Parboosingh JS. Father-to-Son Transmission of an X-linked Gene:A Case of Paternal Sex Chromosome Heterodisomy. Am J Med Genet 149A:2871-2873, 2009.

Lehman AM, Eydoux P, Doherty D, Glass IA, Chitayat D, Chung BYH, Langlois S, Yong SL, Lowry RB, Hildebrandt F, Trnka P. Co-Occurrence of Joubert Syndrome and Jeune Asphyxiating Thoracic Dystrophy. Am J Med Genet Part A 152A:1411-1419, 2010.

Lowry RB. Congenital Anomalies – why bother? Medical Journal of Australia Vol 193 Number 7:428, 2010.

Lowry RB, Sibbald B, Bedard T, Hall JG. Prevalence of Multiple Congenital Contractures Including Arthrogryposis Multiplex Congenita in Alberta, Canada, and a Strategy for Classification and Coding. Birth Defects Research (Part A):Clinical land Molecular Teratology 88:1057-1061, 2010.

Germany, Saxony-Anhalt

Birnbaum, S., Ludwig, K.U., Reutter, H., Herms, S., Steffens, M., Rubini, M., Baluardo, C., Ferrian, M., Almeida de Assis, N., Alblas, M.A., Barth, S., Freudenberg, J., Lauster C., Schmidt, G., Scheer, M., Braumann, B., Bergé, S.J., Reich, R.H., Schiefke, F., Hemprich, A., Pötzsch, S., Steegers-Theunissen, R.P., Pötzsch, B., Moebus, S., Horsthemke, B., Kramer, F.J., Wienker, T.F., Mossey, P.A., Propping, P., Cichon, S., Hoffmann, P., Knapp, M., Nöthen, M.M., Mangold, E.: Key susceptibility locus for nonsyndromic cleft lip with or without cleft palate on chromosome 8q24. In: Nature Genetics (41), 2009, 4, 473-477

Birnbaum, S., Ludwig, K.U., Reutter, H., Herms, S., de Assis, N.A., Diaz-Lacava, A., Barth, S., Lauster, C., Schmidt, G., Scheer, M., Saffar, M., Martini, M., Reich, R.H., Schiefke, F., Hemprich, A., Pötzsch, S., Pötzsch, B., Wienker, T.F., Hoffmann, P., Knapp, M., Kramer, F.-J., Nöthen, M.M., Mangold, E.: IRF6 gene variants in Central European patients with non-syndromic cleft lip with or without cleft palate. In: European Journal of Oral Sciences (117), 2009, 6, 766-769

Birnbaum, S., Reutter, H., Mende, M., de Assis N.A., Diaz-Lacava, A., Herms, S., Scheer, M., Lauster, C., Braumann, B., Schmidt, G., Martini,

M., Hemprich, A.,Pötzsch, S., Knapp, M., Nöthen, M.M., Kramer, F.J., Mangold, E.: Further evidence for the involvement of MYH9 in the etiology of non-syndromic cleft lip with or without cleft palate. In: European Journal of Oral Sciences (117), 2009, 2, 200-203

Krause, H., Pötzsch, S., Haß, H.-J., Gerloff, C., Jaekel, A., Avenarius, S., Kroker, S.: Ventrale Bauchwanddefekte - Darstellung der Entwicklung in Prävalenz und operativem Vorgehen anhand von Gastroschisis und Omphalozele. In: Zentralblatt für Chirurgie (134), 2009; 6, 524-531

Pötzsch, S., Hoyer-Schuschke, J.: Angeborene Fehlbildungen- Hintergrund-wissen für die Beratung der Eltern. In: Die Hebamme (22), 2009, 2, 88-94

Loane, M., Dolk, H., Morris, J.K., EUROCAT Working Group (Pötzsch, S.):
Maternal age-specific risk of non-chromosomal anomalies. In: Br J Gynaecol 116: 2009, 1111-1119

Lindinger A, Schwedler G, Hense HW, for the participants of the PAN study. Prevalence of congenital heart defects in newborns in Germany: results of the first registration year of the PAN study (July 2006 to June 2007). Klinische Pädiatrie 2010: 321–326.

Pötzsch S. 2010. 5. Einsendertreffen des Fehlbildungsmonitoring Sachsen–Anhalt. Ärzteblatt Sachsen–Anhalt 1:19–20.

Pötzsch S, Bretschneider D, Hoyer–Schuschke J, et al. 2010. Neugeborenes mit frontonasaler Schwellung. Monatsschrift Kinderheilkunde 5:427–429.

Iran: TRoCA

Dastgiri S, Salehpoor F, Bigdeli A. An unusual time pattern of central nervous system anomalies in Northwestern Iran. Neurosciences. 2010;15(4):294.

Dastgiri S, Is there an outbreak of neural tube defects happening in Iraq? Saudi Med J. 2010 Jul;31(7):837.

Taghizadeh M, Dastgiri S, Heidarzadeh H. Early diagnosis and screening of congenital heart anomalies. European Journal of Human Genetics, 2010 18: s58.

Dastgiri S. Has Chornobyl explosion had an impact on structural malformations in animal populations?. Pediatrics 2010; 125: e836-e843. (comment)

Dastgiri S, Kalankesh LR, Heidarzadeh H, Tajahmad A, Rezaian E. A new registry of congenital anomalies in Iran. Journal of Registry Management 2010; 37 (1):27-29.

Dastgiri S, Bonyadi M, Mizani T. Prevalence of Genetics Disorders in the northwest of Iran. Urmia Medical Journal, 2010; 21 (4) :339-346.

Dastgiri S, Sheikhzadeh Y, Dastgiri A. Monitoring of congenital anomalies in developing countries: a pilot model in iran. Stud Health Technol Inform. 2011;164:157-61.

Dastgiri S, Taghizadeh M, Heidarzadeh M. Early diagnosis and screening of congenital cardiac anomalies. Cardiology in the Young 2011, 21, 194–196.

Ireland - Dublin EUROCAT Registry

Delany C, McDonnell R, Robson M, Corcoran S, Fitzpatrick C, De La Harpe D. Folic acid supplement use in the prevention of neural tube defects. Irish Medical Journal. 2011 Jan;104(1):12-5.

Northern Netherlans

Ester Garne, Maria Loane, Diana Wellesley, Ingeborg Barisic, EUROCAT Working Group (Marian Bakker). Congenital hydronephrosis: Prenatal diagnosis and epidemiology in Europe. Journal of Pediatric Urology (2009) 5: 47 -52.

Wilma P. van der Roest, José M.Pennings, Marian Bakker, Maarten P. van den Berg and J. Peter van Tintelen. Family letters are an effective way to inform relatives about inherited cardiac disease. American Journal of Medical Genetics (Part A) p357-363

Hermien E.K. de Walle, Ingrid M. van Beynum, Livia Kapusta, Marian K. Bakker, Martin den Heijer, Henk J. Blom. Preventive Effect of Periconceptional Folic Acid Supplementation on the Risk of Congenital Heart Defects: A Registry Based Case-Control Study in the Netherlands [abstract]. Birth Defects Research (Part A) Clinical and Molecular Teratology 85:233-246 (2009)

Ester Garne and Hermien de Walle. Reply to A. Materna-Kiryluk, K. Wisniewska, M. Badura-Stronka, J. Mejnartowics, B. Wieckowska, A. Balcar-Boron. Parental age and congenital malformations. Peadiatric and Perinatal Epidemiology 2009; 23:29-40.

M Loane, H Dolk, JK Morris, a Eurocat Working Group (H de Walle). Maternal age-specific risk of non-chromosomal anomalies. BJOG An International

Journal of Obstetrics and Gynaecology 2009; 116: 1111-1119.

The Eurocat Surveillance of Congenital Anomalies (EUROCAT) Project Working Committee (HEK de Walle). What is the "primary" prevention of congenital anomalies? Lancet August 1-7, 2009 - Vol 374 – Page 378

Yvonne J. Vos, Hermien E.K. de Walle, Krista K. Bos, Jenneke A. Stegeman, Annelies M. ten Berge, Martijn Bruining, Merel C. van Maarle, Mariet W. Elting, Nicolette S. den Hollander, Ben Hamel, Ana Maria Fortuna, Lone E.M. Sunde, Irene Stolte-Dijkstra, Connie T.R.M. Schrander-Stumpel, Robert M.W. Hofstra. Genotype-phenotype correlations in L1 syndrome: a guide for genetic counselling and mutation analysis. J Med Genet 2009.

Jonne J. Sikkens, Manon van Eijsden, P. Dick Bezemer, Marian K. Bakker, Gouke J. Bonsel, Marcel F. van der Wal en Martina C. Cornel. Congenitale afwijkingen in Amsterdam. NTvG 2009; 153:B433

Ingrid M. van Beynum, Livia Kapusta, Marian K. Bakker, Martin de Heijer, Henk J. Blom and Hermien E.K. de Walle. Protective effect of periconceptional folic acid supplements on the risk of congenital heart defects: a registry-based case-control study in the northern Netherlands. European Heart Journal Feb; 31(4)464-71.

Bakker MK, Kerstjens-Frederikse WS, Buys CHCM, Walle HEK de, Jong-van den Berg LTW de. First-trimester use of paroxetine and congenital heart defects: a population-based case-control study. Birth defects research (part A), 2010, 88, 94 - 100

Bakker MK, Walle HEK de, Wilffert B, Jong – van den Berg LTW de. Fluoxetine and infantile hypertrophicpylorus stenosis: a signal from a birth defects – drug exposure surveillance study. Pharmacoepidemiol Drug Saf. 2010 Aug;19(8):808-13.

Beynum IM van, Kaputa L, Bakker MK, Heijer M den, Blom HJ, Walle HEK de. Protective effect of periconceptional folic acid supplements on the risk of congenital heart defects: a registry-based case-control study in the northern Netherlands .Eur Heart J. 2010 Feb;31(4):464-71. Epub 2009 Dec 1.

Bergman JEH, Blake KD, Bakker MK, Marchie Sarvaas GJ du, Free RH, Ravenswaaij-Arts CMA van. Death in CHARGE syndrome after the neonatal period. Clin genet, 2010, 77, 232-240

Garne E, Khoshnood B, Loane M, Boyd PA, Holk H, The Eurocat Working Group (Walle HEK de). Termination of pregnancy for fetal anomaly after 23 weeks of gestation: a european register-based study. BJOG, 2010; 117: 660 – 669

Jentink J, Bakker MK, Nijenhuis CM, Wilffert B. Does folic acid use decrease the risk for spina bifrida after in utero exposure to valproic acid? Pharmacoepidemiol Drug Saf. 2010 Aug;19(8):803-7.

Jentink J, Dolk H, Loane MA, Morris JK, Wellesly D, Garne E, Jong– van de Berg D de, Eurocat Working Group (MK bakker). Intrauerine exposure to carbamazepine and specific congenital malformations: systematic review and casecontrol study. BMJ, 2010; 341: 1-7

Jentink J, Loane MA, Dolk H, Barisic I, Garne E, Morris JK, de Jong-van den Berg LT; EUROCAT Antiepileptic Study Working Group (MK Bakker). Valproic acid monotherapy in pregnancy and major congenital malformations. N Engl J Med. 2010 Jun 10;362(23):2185-93.

Souza E de, Morris JK, EUROCAT Working Group (Bakker MK). Case – control analysis of paternal age and trisomic anomalies. Arch Dis Child. 2010 Nov;95(11):893-7. Epub 2010 Jun 28

Spaendonck – Zwarts KY van, Hessem L van, Jongbloed JDH, Walle HEK de, Capetanaki Y, Kooi AJ van der, Langen IM van, Berg MP van den, Tintelen JP van. Desmin – related myopathy: a review and meta-analysis. Clin Genet. 2010 Jul 21. [Epub ahead of print]

Vos YJ, Walle HEK de, Bos KK, Stegeman JA, Berge AM ten, Bruining M, Maarle MC van, Elting MW, Hollander NS den, Hamel B, Fortuna AM, Sunde LEM, Stolte-Dijkstra I, Schrander-Stumpel CTRM, Hofstra RMW. Genotype-phenotype correlations in L1 syndrome: a guide for genetic counselling and mutation analysis. J Med Genet. 2010 Mar;47(3):169-75. Epub 2009 Oct 20.

South America: ECLAMC

Wehby GL, Murray JC, Castilla EE, Lopez-Camelo JS, Ohsfeldt RL. Prenatal care demand and its effects on birth outcomes by birth defect status in Argentina. Econ Hum Biol. 7:84-95; 2009.

Orioli IM, Mastroiacovo P, López-Camelo JS, Saldarriaga W, Isaza C, Aiello H, Zarante I, Castilla EE. Clusters of Sirenomelia in South America. Birth Defect Res-A; 85:112-118; 2009.

Wehby GL, Murray JC, Castilla EE, Lopez-Camelo

JS, Ohsfeldt RL. Quantile effects of prenatal care utilization on birth weight in Argentina. Health Econ. 18: 1307-1321; 2009.

Castilla E, Orioli M. Classification system for cleft lip and palate. Cleft Palate Craniofac J 46: 220, 2009. Wehby GL, Murray JC, Castilla EE, Lopez-Camelo JS, Ohsfeldt RL. Prenatal care effectiveness and utilization in Brazil. Health Policy Plan. 24: 175-188; 2009.

Wehby GL, Castilla EE, Lopez-Camelo JS, Murray JC. Predictors of multivitamin use during pregnancy in Brazil. Int J Public Health. 54:78-87; 2009.

Neiswanger K, Chirigos KW, Klotz CM, Cooper ME,Bardi KM,Brandon CA, Weinberg SM, Vieira AR, Martin RA, Czeizel AE, Castilla EE, Poletta FA, Marazita ML. Whorl patterns on the lower lip are associated with nonsyndromic cleft lip with or without cleft palate. Am J Med Genet-A 149: 2673-2679, 2009.

Kadir MM, McClure EM, Goudar SS, Garces AL, Moore J, Onyamboko M, Kaseba C, Althabe F, Castilla EE, Freire S, Parida S, Saleem S, Wright LL, Goldenberg RL. Exposure of pregnant women to indoor air pollution: a study from nine low and middle income countries. Acta Obstet Gynecol Scand. 89:540-548; 2009.

Bronberg RA, Dipierri JE, Alfaro EL, Barrai I, Rodríguez-Larralde A, Castilla EE, Rodríguez-Arroyo G, Bailliet G.. Isonimy structure of Buenos Aires City. Human Biology 81:447-461; 2009.

Campaña H, Ermini M, Aiello HA, Krupitzki H, Castilla EE, López-Camelo JS; Latin American Collaborative Study of Congenital Malformations Study Group. Prenatal sonographic detection of birth defects in 18 hospitals from South America.J Ultrasound Med. 29:203-212; 2010..

Orioli IM and Castilla EE. Epidemiology of Holoprosencephaly: Prevalence and Risk Factors. Am J Med Genet-C, 154C: 13-21; 2010.

Poletta, FA; López-Camelo JS; Gili, JA; Montalvo G; Castilla EE, Red del Estudio Colaborativo Latinoamericano de Malformaciones Congénitas en Ecuador. Consumo y exposición al humo de tabaco en mujeres embarazadas de Ecuador. Rev Panam Salud Publica 27: 56–65; 2010.

Beaty TH, Murray JC, Marazita ML, Munger RG, Ruczinski I, Hetmanski JB, Liang KY, Wu T, Murray T, Fallin MD, Redett RA, Raymond G, Schwender H, Jin SC, Cooper ME, Dunnwald M, Mansilla MA, Leslie E, Bullard S, Lidral AC, Moreno LM, Menezes R, Vieira AR, Petrin A, Wilcox AJ, Lie RT, Jabs EW, Wu-Chou YH, Chen PK, Wang H, Ye X, Huang S, Yeow V, Chong Samuel S, Jee SH, Shi B, Christensen K, Melbye M, Doheny KF, Pugh EW, Ling H, Castilla EE, Czeizel AE, Ma L, Field LL, Brody L, Pangilinan F, Mills JL, Molloy AM, Kirke PN, Scott JM, Arcos-Burgos M, Scott AF. A genome-wide association study of cleft lip with and without cleft palate identifies risk variants near *MAFB* and *ABCA4*. Nature Genetics. 42: 525-529; 2010.

Letra A, Menezes R, Fonseca RF, Govil M, McHenry T, Murphy MJ, Hennebold JD, Granjeiro JM, Castilla EE, Orioli IM, Martin R, Marazita ML, Bjork BC, Vieira AR. Novel Cleft Susceptibility Genes in Chromosome 6q. J Dent Res 89: 927–932. 2010.

Letra A, Menezes R, Govil M, Fonseca RF, McHenry T, Granjeiro JM, Castilla EE, Orioli IM, Marazita ML, Vieira AR. Follow-Up Association Studies of Chromosome Region 9q and Nonsyndromic Cleft Lip/Palate. Am J Med Genet A, 152A:1701-1710; 2010.

Wehby G, Castilla EE, Lopez-Camelo JS. The Impact of Altitude on Infant Health in South America. Economics and Human Biology. 8: 197-211; 2010.

López-Camelo, J. S., Castilla, E. E. and Orioli, I. M. , Folic acid flour fortification: Impact on the frequencies of 52 congenital anomaly types in three South American countries. Am J Med Genet A, 152A: 2444-2458; 2010.Letra AM, Menezes R, Cooper ME, Fonseca RF, Tropp S, Govil M, Granjeiro JM, Imoehl SR, Mansilla MA, Murray JC, Castilla EE, Orioli IM, Czeizel AE, Ma L, Chiquet BT, Hecht JT, Vieira AR, Marazita ML. *CRISPLD2* variants including a C471T silent mutation may contribute to nonsyndromic cleft lip with or without cleft palate. Cleft Palate Craniofac J. 2010 Jul 1 [Epub ahead of print].

Spain: ECEMC

Aceña MI, MacDonald A, Rodríguez L, Martínez-Fernández ML, Martínez Carrascal A, Zollino M, Martínez-Frías ML. Reordenamientos cromosómicos complejos (CCRs): Presentación de un nuevo caso con 5 puntos de rotura entre los cromosomas 4 y 8. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:54-62. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Alías L, Bernal S, Fuentes-Prior P, Barceló MJ, Also E, Martínez-Hernández R, Rodríguez-Alvarez FJ, Martín Y, Aller E, Grau E, Peciña A, Antiñolo G, **Galán E**, Rosa AL, Fernández-Burriel M, Borrego S,

Millán JM, Hernández-Chico C, Baiget M, Tizzano EF. Mutation update of spinal muscular atrophy in Spain: molecular characterization of 745 unrelated patients and identification of four novel mutations in the SMN1 gene. Hum Genet 2009;125,1:29-39.

Bermejo E, Cuevas L, Grupo Periférico del ECEMC, Martínez-Frías ML. Vigilancia epidemiológica de anomalías congénitas en España: Análisis de los datos del registro del ECEMC en el período 1980-2008. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:64-91. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Bermejo E, Martínez-Frías ML. Situación actual en España sobre el diagnóstico etiológico en fetos procedentes de abortos por defectos congénitos. Directrices para un protocolo mínimo. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:18-23. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Bermejo E, Mendioroz J, Cuevas L, Martínez-Frías ML. Congenital Defects Associated with Congenital Diaphragmatic Hernia (CDH): Multivariate Analysis on a Large Series of Newborn Infants in Spain. Birth Defects Res A Clin Mol Teratol 2009;85,3:240-240.

Carrascosa Romero MC, Barros Angueira F, Castillo Serrano A, Fernández Córdoba MS, Sorli García S, Quintanilla Mata ML. Síndrome de Mowat-Wilson con una deleción en el gen ZEB2 no descrita previamente. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:9-17. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Esteban Marfil MV, Martínez Espinosa N, Santiago Gutiérrez C, Sierra Córcoles C, Cruz Moreno J. de la, Sanchis Calvo A, Crow YJ, Martínez-Frías ML. Síndrome de Aicardi-Goutières de presentación neonatal simulando infección congénita. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:2-8. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Fernández Martín P, Rodríguez-Pinilla E, Mejías Pavón C, García Benítez MR, Real Ferrero MM, Ortega Mateo A, Martínez-Frías ML. Actividad de los servicios de información sobre teratógenos (SITTE y SITE) durante el año 2008. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:116-119. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

González de Dios J, Aleixandre-Benavent R. El análisis cienciométrico de las publicaciones biomédicas sobre genética y dismorfología clínica. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:134-145. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Iglesias Escalera G, Carrasco Marina ML, Martín Del Valle F, Martínez Guardia N, Rodríguez L, Martínez-Fernández ML. Síndrome de Miller-Dieker. An Pediatr (Barc) 2009;70,3:304-306. (Letter to the Editor. In Spanish)

Martínez-Fernández ML, Rodríguez L, Aceña MI, MacDonald A, Centeno F, Lapunzina P, Martínez-Frías ML. Paciente con Síndrome de Cri-Du-Chat y de Beckwith-Wiedemann originado por un derivado de translocación paterna. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:46-53. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Martínez-Frías ML. Comentario editorial: El lado "perverso" del factor de impacto en la investigación biomédica en nuestro país. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:132-133. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Martínez-Frías ML. Conjoined twins presenting with different sex: Description of a second case that truly represents the earliest historical evidence in humans. Am J Med Genet Part A 2009;149A:1595-1596.

Martínez-Frías ML. Correspondence to the authors: Topiramate in pregnancy: Preliminary experience from the UK Epilepsy and Pregnancy Register. Neurology 2009; 72,23:2054-2055.

Martínez-Frías ML and the ECEMC Working Group. Epidemiology of acephalus/acardius monozygotic twins: New insights into an epigenetic causal hypothesis. Am J Med Genet Part A 2009;149A:640-649.

Martínez-Frías ML, Bermejo E. Análisis clínico de los recién nacidos con defectos congénitos registrados en el ECEMC: Distribución por etiología y por grupos étnicos. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:24-44. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Martínez-Frías ML, Bermejo E, Grupo Periférico del ECEMC. Características de las madres que siguieron técnicas de reproducción asistida. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:92-103. (In

Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Martínez-Frías ML, Bermejo E, Mendioroz J, Rodríguez-Pinilla E, Blanco M, Egüés J, Félix V, García A, Huertas H, Nieto C, López JA, López S, Paisán L, Rosa A, Vázquez MS. Epidemiological and clinical analysis of a consecutive series of conjoined twins in Spain. J Ped Surg 2009; 44:811-820.

Martínez-Frías ML, Bermejo E, Rodríguez-Pinilla E and ECEMC Working Group. Letter to the Editor: Human genetics selection for the MTHFR 677>T polymorfism: A leap in the dark. 2009 February. Access throught: http://www.biomedcentral.com/1471-2350/9/104/comments

Martínez-Frías ML, Rodríguez-Pinilla E. Editorial: Gripe A (H1N1) en mujeres embarazadas: Hechos conocidos, desconocidos, y evaluación beneficios-riesgos. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:V-X. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Mejías Pavón C, Rodríguez-Pinilla E, Fernández Martín P, Ortega Mateo A, García Benítez MR, Real Ferrero MM, Grupo Periférico del ECEMC, Martínez-Frías ML. Fármacos antipsicóticos y embarazo: resumen de la literatura y experiencia en el ECEMC. Bol. ECEMC: Rev Dismor Epidemiol 2009;V,8:106-113. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2009_AF.PDF)

Rodríguez L, Martínez-Fernández ML, Aceña MI, López Mendoza S, Martín Fumero L, Rodríguez de Alba M, Gallego-Merlo J, Martínez-Frías ML. Dicentric inverted duplication of entire 4p arm with no apparent deletion and internal placing of the (-TTAGGG-)n sequence: Description of the first patient. Am J Med Genet Part A 2009;149A:1058-1061.

Valencia M, Lapunzina P, Lim D, Zannolli R, Bartholdi D, Wollnik B, Al-Ajlouni O, Eid SS, Cox H, Buoni S, Hayek J, Martínez-Frías ML, Antonio PA, Temtamy S, Aglan M, Goodship JA, Ruiz-Perez VL. Widening the mutation spectrum of EVC and EVC2: ectopic expression of Weyer variants in NIH 3T3 fibroblasts disrupts hedgehog signaling. Hum Mutat 2009;30,12:1667-1675.

Aceña I, MacDonald A, Martínez-Fernández ML, Bermejo E, Martínez-Frías ML. Análisis clínico-epidemiológico de las niñas recién nacidas con síndrome de Turner y de aquellas con tres cromosomas X. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:55-66. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Bermejo E. Valoración de teratógenos y pautas a seguir ante el niño prenatalmente expuesto a un teratógeno. In: Protocolos diagnósticos y terapéuticos en Pediatría. Tomo 1: Genética Clínica, Dismorfología y Neurología. 2nd. ed. Ed. Exlibris, 2010. pp. 107-115 (ISSN: 2171-8172). (In Spanish)

Bermejo Sánchez E. Frecuencias de defectos congénitos al nacimiento en España y su comportamiento temporal y por comunidades autónomas. Causas de las variaciones de las frecuencias. Semergen 2010;36,8: 449-455. (In Spanish. Abstract in English)

Bermejo E, Cuevas L, Grupo Periférico del ECEMC, Martínez-Frías ML. Informe de Vigilancia Epidemiológica de anomalías congénitas en España: Datos registrados por el ECEMC en el período 1980-2009. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:68-100. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Bermejo E, Martínez-Frías ML. Prevention, diagnosis and services. Adv Exp Med Biol 2010; 686:55-75.

Climent Alcalá FJ, Molina Rodríguez MA, González Casado I, Osona Bris L, Salamanca Fresno L, Guerrero-Fernández J, Martínez-Frías ML, Gracia Bouthelier R. Deleción del cromosoma 9p-. Disgenesia gonadal asociada a retraso mental e hipoplasia del cuerpo calloso. ¿Síndrome de genes contiguos? An Pediatr (Barc) 2010;72,3:210-214. (In Spanish. Abstract in English)

Cid Galache P, Gómez Vida JM, Olivares Sánchez L, Pérez Iañez R, Casas Gómez J, Broncano Lupiañez S, Rodríguez Leal A. Fosa nasal supernumeraria, una extraña malformación congénita. Primer caso registrado por el ECEMC. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:15-19. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Fernández-Toral J, Rodríguez L, Plasencia A, Martínez-Frías ML, Ewers E, Hamid AB, Ziegler M, Liehr T. Four small supernumerary marker chromosomes derived from chromosomes 6, 8, 11 and 12 in a patient with minimal clinical abnormalities: a case report. J Med Case Reports 2010;4:239.

González de Dios J, Bermejo E, Mestre J, Ruipérez

C, Moya M, Cuevas L, Martínez-Frías ML. Síndrome de Desorganización: Características y descripción del primer caso registrado en el ECEMC. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:9-14. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

MacDonald AH, Rodríguez L, Aceña I, Martínez-Fernández ML, Sánchez-Izquierdo D, Zuazo E, Martínez-Frías ML. Subtelomeric deletion of 12p: Description of a third case and review. Am J Med Genet Part A 2010;152A:1561-1566.

Martínez-Fernández ML, Bermejo E, Martínez-Frías ML. Ejemplos clínicos de alteraciones crípticas del ADN, y guías para sospechar que un niño pueda tener alguna alteración críptica o molecular. Semergen 2010;36,10:573-578. (In Spanish. Abstract in English)

Martínez-Fernández ML, Sánchez-Izquierdo MD, Martínez-Frías ML. Resumen de la evolución de las técnicas de citogenética y genética molecular para la identificación de las alteraciones genéticas del desarrollo embrionario. Semergen 2010;36,9:520-525. (In Spanish. Abstract in English)

Martínez-Frías ML. Editorial: La prevención de defectos congénitos en Atención Primaria. Semergen 2010;36,3:119-120. (In Spanish. Abstract in English)

Martínez-Frías ML. Características generales de los defectos congénitos, terminología y causas. Semergen 2010;36,3:135-139. (In Spanish. Abstract in English)

Martínez-Frías ML. Actualización de conocimientos sobre formación de los gametos. Procesos de meiosis y fecundación. Semergen 2010;36,4:216-220. (In Spanish. Abstract in English)

Martínez-Frías ML. Estructura y función del ADN y de los genes. I Tipos de alteraciones de la función del gen por mutaciones. Semergen 2010;36,5:273-277. (In Spanish. Abstract in English)

Martínez-Frías ML. Estructura y función del ADN y de los genes. II Tipos de alteraciones de la función del gen por procesos epigenéticos. Semergen 2010;36,6:332-335. (In Spanish. Abstract in English)

Martínez-Frías ML. Can our understanding of epigenetics assist with primary prevention of congenital defects? J Med Genet 2010;47:73-80.

Martínez-Frías ML, Bermejo E, Cuevas L, Grupo Periférico del ECEMC. Análisis clínico-epidemiológico de los recién nacidos con defectos congénitos registrados en el ECEMC: Distribución por etiología y por grupos étnicos. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:20-42. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Martínez-Frías ML, de Frutos CA, Bermejo E, ECEMC Working Group, Nieto MA. Review of the recently defined molecular mechanisms underlying Thanatophoric Dysplasia and their potential therapeutic implications for Achondroplasia. Am J Med Genet Part A 2010;152A:245-255.

Mejías Pavón C, Rodríguez-Pinilla E, Fernández Martín P, Real Ferrero MM, García Benítez MR, Martínez-Frías ML. Actividad de los Servicios de Información sobre Teratógenos (SITTE y SITE) durante el año 2009. Análisis de la utilización del SITTE por los distintos especialistas médicos. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:112-117. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Rodríguez-Pinilla E, Martínez-Frías ML. Tratamiento farmacológico de la mujer embarazada: fármacos contraindicados durante el embarazo. Semergen 2010; 36,10:579-585. (In Spanish. Abstract in English)

Rodríguez-Pinilla E, Real Ferrero MM, Mejías C, García Benítez MR, Fernández P, Grupo Periférico del ECEMC y Martínez-Frías ML. Consumo de Cafeína en el Embarazo en Nuestro Medio y Riesgo para el Desarrollo Embrionario/Fetal. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:102-110. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Romanelli V, Belinchón A, Benito-Sanz S, Martínez-Glez V, Gracia-Bouthelier R, Heath KE, Campos-Barros A, García-Miñaur S, Fernández L, Meneses H, López-Siguero JP, Guillén-Navarro E, Gómez-Puertas P, Wesselink J-J, Mercado G, Esteban-Marfil V, Palomo R, Mena R, Sánchez A, del Campo M, Lapunzina P. *CDKN1C* ($p57^{Kip2}$) analysis in Beckwith-Wiedemann syndrome (BWS) patients: Genotype-phenotype correlations, novel mutations, and polymorphisms. Am J Med Genet Part A 2010;152A,6:1390-1397.

Sánchez-Izquierdo MD, Martínez-Fernández ML, Martínez-Frías ML. ¿Qué son los Microarrays? Aplicación al diagnóstico de anomalías congénitas. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:48-54. (In Spanish. Abstract in English.

Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Sanchis A, Martínez Castellano F, Aleu M, Pí G, Ballester E. Síndrome de Coffin-Lowry: Presentación de un caso y Guías Diagnóstico-evolutivas y Anticipatorias. Bol ECEMC: Rev Dismor Epidemiol; 2010,V,9:2-8. (In Spanish. Abstract in English. Access through http://www.ciberer.es/documentos/ECEMC_2010_AF.pdf)

Ukraine, OMNI-Net

Publications

Kfir M, Yevtushok L, Onishchenko S, Wertelecki W, Bakhireva L, Chambers C D, Jones K L, and Hull A D. *Can Prenatal Ultrasound Detect the Effects of In Utero Alcohol Exposure? – A pilot study.* Ultrasound in Obstetrics and Gynecology. 2009 Jun;33(6);683-9.

Wertelecki W. *Malformations in a Chornobyl-Impacted Region.* Pediatrics. 2010 Apr;125(4): e836-43.

Keen C L, Uriu-Adams J Y, Skalny A, Grabeklis A, Grabeklis S, Green K, Yevtushok L, Wertelecki W, and Chambers C D. *The Plausibility of Maternal Nutritional Status Being a Contributing Factor to the Risk for Fetal Alcohol Spectrum Disorders: the Potential Influence of Zinc Status as an Example. Biofactors.* 2010 Mar;36(2):125-35. Review.

Dancause K N, Yevtushok L, Lapchenko S, Shumlyansky L, Shevchenko G, Wertelecki W, and Garruto R M. *Chronic radiation exposure in the Rivne-Polissia region of Ukraine: implications for Birth Defects.* Am J Hum Biol. 2010 Sep-Oct; 22(5):667-74.

Uriu-Adams J Y, Chambers C D, Gross H B, Ensunsa J L, Green K Le A, Yevtushok L, Zymak-Zakutnya N, and Wertelecki W. *Alcohol Drinking Patterns and Nutrient Status in Ukrainian Pregnant Women. Birth Defects Research (Part A):* Clinical and Molecular Teratology. 2010;88:382.

Abstracts and Presentations

Needham K D, Yevtushok L, Lapchenko S, Wertelecki W, and Garruto R M. *Dietary and Activity Patterns and Implications for Birth Defects in the Chernobyl Impacted Rivne-Polissia Region of Ukraine.* American Journal of Human Biology 2009;21:261-262.

Wertelecki W, et al. *Neural Tube Defects (NTD) in a Chornobyl Impacted Region.* Proceedings of the 6th International NTD Conference; 2009 September 12-15; Burlington, VT. Abstract.

Chambers C, Yevtushok L, Bakhireva L, Prewitt L, Wertelecki W, and Jones K. *Correlation of Prenatal Alcohol Dose with Physical Features of FASD in Infants Born to Women in Ukraine.* 32nd Annual Research Society on Alcoholism Scientific Conference, San Diego, CA, Alcohol Clin Exp Res, 2009, June 20-24, 33(Suppl 1):11A-346A. A116

Chambers C D, Uriu-Adams J Y, Keen C L, Yevtushok L, and Wertelecki W. *Micronutrient Levels in Plasma in Mid-Gestation Vary by Quantity of Alcohol Consumption in Pregnant Women in Ukraine.* 32nd Annual of the Research Society on Alcoholism Scientific Conference, San Diego, CA, Alcohol Clin Exp Res, 2009, June 20-24, 33(Suppl 1)11A-346A. A117.

Chambers C D, Uriu-Adams J Y, Gross H B, Ensunsa J L, Green K, Le A, Yevtushok L, Zymak N, Wertelecki W, and Keen C L. *Altered Maternal Nutritional Factors May Confer Risk of Fetal Alcohol Spectrum Disorders (FASD).* ACER 2010 June;34 Supp:293A.

Wertelecki W, Yevtushok L, Zymak-Zakutnya N, and Lapchenko S. *Experience in a Region Impacted by Chornobyl Chronic Low Dose Radiation.* 1st European Congress on Preconception Care and Preconception Health, Brussels, 6-9 October 2010. Book of Abstracts, p. 113

USA, Atlanta: MACDP

Ahluwalia IB, Harrison L, Jamieson D, Rasmussen SA. Influenza vaccine usage by pregnant women in Georgia and Rhode Island: Evidence from the Pregnancy Risk Assessment Monitoring System—2004 to 2007. MMWR Morb Mortal Wkly Rep. 2009;58(35):972-5.

Ahluwalia, I. B., Jamieson, D. J., Rasmussen, S. A., D'Angelo, D., Goodman, D., & Kim, H. Correlates of Seasonal Influenza Vaccine Coverage Among Pregnant Women in Georgia and Rhode Island. Obstet Gynecol. 2010;116(4), 949-55.

Allen EG, Freeman SB, Druschel C, Hobbs CA, O'Leary LA, Romitti PA, Royle MH, Torfs CP, Sherman SL. Maternal age and risk for trisomy 21 assessed by the origin of chromosome nondisjunction: a report from the Atlanta and National Down Syndrome Projects. Hum Genet. 2009;125(1):41-52.

Alwan S, Reefhuis J, Botto LD, Rasmussen SA, Correa A, Friedman JM, and the National Birth Defects Prevention Study. Maternal use of

bupropion and risk for congenital heart defects. Am J Obstet Gynecol. 2010;203(1):52.e1-6.

Alwan S, Reefhuis J, Rasmussen SA, Friedman JM; National Birth Defects Prevention Study. Patterns of antidepressant medication use among pregnant women in a United States population. J Clin Pharmacol. 2011;51(2):264-70.

Anderka MT, Lin AE, Abuelo DN, Mitchell AA, Rasmussen SA. Reviewing the evidence for mycophenolate mofetil as a new teratogen: case report and review of the literature. Am J Med Genet A. 2009;149A(6):1241-8.

Boulet S, Gambrell D, Shin M, Mathews T, Honein, M. Racial/Ethnic Differences in the Birth Prevalence of Spina Bifida-United States, 1995–2005, MMWR Morb Mortal Wkly Rep. 2009;57(53):1409-13.

Boulet S, Gambrell D, Shin M, Mathews T, Honein, M. Racial/Ethnic Differences in the Birth Prevalence of Spina Bifida-United States, 1995–2005, JAMA. 2009;301(21):2203-4.

Boulet SL, Boyle CA, Schieve LA. Health care use and health and functional impact of developmental disabilities among US children, 1997-2005. Arch Pediatr Adolesc Med. 2009;163(1):19-26.

Boulet SL, Grosse SD, Honein MA, Correa-Villaseñor A. Children with orofacial clefts: health-care use and costs among a privately insured population. Public Health Rep. 2009;124(3):447-53.

Boulet SL, Rasmussen SA, Honein MA; National Birth Defects Prevention Study. Maternal body mass index as a risk factor for craniosynostosis (research letter). Am J Med Genet A. 2010;152A(11):2895-7.

Boulet SL, Schieve LA, Boyle CA. Birth weight and health and developmental outcomes in US children, 1997-2005. Matern Child Health J. 2009 Nov 10. [Epub ahead of print] Can't find the pages

Broussard CS, Louik C, Honein MA, Mitchell AA Herbal use before and during pregnancy. Am J Obstet Gynecol. 2010;202:443.e1-6.

Browne ML, Rasmussen SA, Hoyt AT, Waller DK, Druschel CM, Caton AR, Canfield MA, Lin AE, Carmichael SL, Romitti PA; National Birth Defects Prevention Study. Maternal thyroid disease, thyroid medication use, and selected birth defects in the National Birth Defects Prevention Study. Birth Defects Res A Clin Mol Teratol. 2009;85(7):621-8.

Carmichael SL, Rasmussen SA, Lammer EJ, Ma C, Shaw GM, and the National Birth Defects Prevention Study. Craniosynostosis and nutrient intake during pregnancy. Birth Defects Res Part A Clin Mol Teratol. 2010;88:1032-9.

Carmichael SL, Rasmussen SA, Shaw GM. Prepregnancy obesity: a complex risk factor for selected birth defects. Birth Defects Res A Clin Mol Teratol. 2010;88(10):804-10.

Carmichael SL, Yang W, Correa A, Olney RS, Shaw GM; National Birth Defects Prevention Study. Hypospadias and intake of nutrients related to one-carbon metabolism. J Urol. 2009;181(1):315-21; discussion 321.

Caspers KM, Oltean C, Romitti PA, Sun L, Pober BR, Rasmussen SA, Yang W, Druschel C, and the National Birth Defects Prevention Study. Maternal periconceptional exposure to cigarette smoking and alcohol consumption and congenital diaphragmatic hernia. Birth Defects Res Part A Clin Mol Teratol. 2010;88:1040-9.

Centers for Disease Control and Prevention (CDC). Racial/ethnic differences in the birth prevalence of spina bifida - United States, 1995-2005. MMWR Morb Mortal Wkly Rep. 2009;57(53):1409-13. Erratum in: MMWR Morb Mortal Wkly Rep. 2009;58(3):61.

Cogswell ME, Bitsko RH, Anderka M, Caton AR, Feldkamp ML, Hockett Sherlock SM, Meyer RE, Ramadhani T, Robbins JM, Shaw GM, Mathews TJ, Royle M, Reefhuis J; National Birth Defects Prevention Study. Control selection and participation in an ongoing, population-based, case-control study of birth defects: the National Birth Defects Prevention Study. Am J Epidemiol. 2009;170(8):975-85.

Cogswell ME, Looker AC, Pfeiffer CM, Cook JD, Lacher DA, Beard JL, Lynch SR, Grummer-Strawn LM. Assessment of iron deficiency in US preschool children and nonpregnant females of childbearing age: National Health and Nutrition Examination Survey 2003-2006. Am J Clin Nutr. 2009;89(5):1334-42.

Cogswell ME, Power ML, Sharma A, Schulkin J. Prevention and Management of Obesity in Non-Pregnant Women and Adolescents, Beliefs and Practices of US Obstetricians and Gynecologists, 2005 to 2007. J Womens Health (Larchmt). 2010;19(9):1625-34.

Collier SA, Browne ML, Rasmussen SA, Honein MA; National Birth Defects Prevention Study. Maternal caffeine intake during pregnancy and orofacial clefts. Birth Defects Res A Clin Mol Teratol. 2009;85(10):842-9.

Collier SA, Rasmussen SA, Feldkamp ML, Honein MA; National Birth Defects Prevention Study. Prevalence of self-reported infection during pregnancy among control mothers in the National Birth Defects Prevention Study. Birth Defects Res A Clin Mol Teratol. 2009;85(3):193-201.

Collins JS, Canfield MA, Pearson K, Kirby RS, Case AP, Mai CT, Major J, Mulinare J; National Birth Defects Prevention Network. Public health projects for preventing the recurrence of neural tube defects in the United States. Birth Defects Res A Clin Mol Teratol. 2009;85(11):935-8.

Correa A, Kirby RS. An expanded public health role for birth defects surveillance. Birth Defects Res A Clin Mol Teratol. 2010;88(12):1004-7.

Cragan JD, Gilboa SM. Including prenatal diagnoses in birth defects monitoring: Experience of the Metropolitan Atlanta Congenital Defects Program. Birth Defects Res A Clin Mol Teratol. 2009;85(1):20-9.

Creanga AA, Johnson T, Graitcer S, Hartman L, Al-Samarrai T, Schwarz AG, Chu SY, Sackoff J, Jamieson DJ, Fine AD, Shapiro-Mendoza CK, Jones LE, Uyeki TM, Balter S, Bish CL, Finelli L, Honein MA. Severity of pandemic 2009 H1N1 influenza infection in pregnant women: New York City, May-June 2009. Obstet Gynecol. 2010;115(4):717-26.

Crider KS, Cleves MA, Reefhuis J, Berry RJ, Hobbs CA, Hu DJ. Antibacterial medication use during pregnancy and risk of birth defects: National Birth Defects Prevention Study. Arch Pediatr Adolesc Med. 2009;163(11):978-85.

Darrow LA, Klein M, Flanders WD, Waller LA, Correa A, Marcus M, Mulholland JA, Russell AG, Tolbert PE. Ambient air pollution and preterm birth: a time-series analysis. Epidemiology. 2009;20(5):689-98.

Darrow LA, Strickland MJ, Klein M, Waller LA, Flanders WD, Correa A, Marcus M, Tolbert PE. Seasonality of birth and implications for temporal studies of preterm birth. Epidemiology. 2009;20(5):699-706.

Dolan SM, Callaghan WM, Rasmussen SA. Birth defects and preterm birth: overlapping outcomes with a shared strategy for research and prevention. Birth Defects Res A Clin Mol Teratol. 2009;85(11):874-8.

Dott M, Rasmussen SA, Hogue CJ, Reefhuis J; National Birth Defects Prevention Study. Association Between Pregnancy Intention and Reproductive-health Related Behaviors Before and After Pregnancy Recognition, National Birth Defects Prevention Study, 1997-2002. Matern Child Health J. 2010;14(3):373-81.

Duke CW, Correa A, Romitti PA, Martin J, Kirby RS. Challenges and priorities for surveillance of stillbirths: a report on two workshops. Public Health Rep. 2009;124(5):652-9.

Duke W, Shin M, Correa A, Alverson CJ. Survey of knowledge, attitudes, and practice management patterns of Atlanta-area obstetricians regarding stillbirth, Women's Health Issues. 2010;20(5):366-70.

Duwe K, Reefhuis J, Honein MA, Schieve L, Rasmussen SA, and the National Birth Defects Prevention Study. Epidemiology of fertility treatment use among women with live-born infants, 1997-2003. J Womens Health (Larchmt). 2010;19(3):407-16.

Fine A, Dentinger C, Johnson TF, Kossowski A, Steiner-Sichel L, Schwarz AG, Hartman LK, Honein MA, Jamieson D, Uyeki T, Al-Samarrai T, AA Creanga, SB Graitcer. 2009 Pandemic Influenza A (H1N1) in Pregnant Women Requiring Intensive Care – New York City, 2009. MMWR Morb Mortal Wkly Rep. 2010;59(11):321-6.

Frøen JF, Gordijn SJ, Abdel-Aleem H, Bergsjø P, Betran A, Duke CW, Fauveau V, Flenady V, Hinderaker SG, Hofmeyr GJ, Jokhio AH, Lawn J, Lumbiganon P, Merialdi M, Pattinson R, Shankar A. Making stillbirths count, making numbers talk – issues in data collection for stillbirths. BMC Pregnancy Childbirth. 2009;9:58.

Frøen JF, Pinar H, Flenady V, Bahrin S, Charles A, Chauke L, Day K, Duke CW, Facchinetti F, Fretts RC, Gardener G, Gilshenan K, Gordijn SJ, Gordon A, Guyon G, Harrison C, Koshy R, Pattinson RC, Petersson K, Russell L, Saastad E, Smith GC, Torabi R. Causes of death and associated conditions (Codac): a utilitarian approach to the classification of perinatal deaths. BMC Pregnancy Childbirth. 2009;9:22.

Genisca AE, Frías JL, Broussard CS, Honein MA, Lammer EJ, Moore CA, Shaw GM, Murray JC, Yang W, Rasmussen SA; National Birth Defects Prevention Study. Orofacial clefts in the National Birth Defects Prevention Study, 1997-2004. Am J Med Genet A. 2009;149A(6):1149-58.

Gilboa SM, Correa A, Botto LD, Rasmussen SA, Waller DK, Hobbs CA, Cleves MA, Riehle-Colarusso TJ, and the National Birth Defects Prevention Study. Association between prepregnancy body

mass index and congenital heart defects. Am J Obstet Gynecol. 2010;202:51.e1-51.e10.

Gilboa SM, Salemi JL, Nembhard WN, Fixler DE, Correa A. Mortality due to congenital heart disease among children and adults in the United States, 1999-2006. Circulation. 2010;122(22):2254-63.

Gilboa SM, Strickland MJ, Olshan AF, Werler MM, Correa A; National Birth Defects Prevention Study. Use of antihistamine medications during early pregnancy and isolated major malformations. Birth Defects Res A Clin Mol Teratol. 2009;85(2):137-50.

Hamner HC, Mulinare J, Cogswell ME, Flores AL, Boyle CA, Prue CE, Wang CY, Carriquiry AL, Devine O. Predicted contribution of folic acid fortification of corn masa flour to the usual folic acid intake for the US population: National Health and Nutrition Examination Survey 2001-2004. Am J Clin Nutr. 2009;89(1):305-15.

Hamrick SE, Strickland MJ, Shapira SK, Autry A, Schendel D. Use of special education services among children with and without congenital gastrointestinal anomalies. Am J Intellect Dev Disabil. 2010;115(5):421-32.

Hinton CF, Ojodu JA, Fernhoff PM, Rasmussen SA, Scanlon KS, Hannon WH. Maternal and Neonatal Vitamin B12 Deficiency Detected through Expanded Newborn Screening-United States, 2003-2007. J Pediatr. 2010;157(1):162-3.

Honein MA, Kirby RS, Meyer RE, Xing J, Skerrette NI, Yuskiv N, Marengo L, Petrini JR, Davidoff MJ, Mai CT, Druschel CM, Viner-Brown S, Sever LE; National Birth Defects Prevention Network. The association between major birth defects and preterm birth. Matern Child Health J. 2009;13(2):164-75.

Honein MA, Rasmussen SA. Epidemiological Studies of Congenital Heart Defects: Challenges and Opportunities. Congenital Heart Defects: From Origin to Treatment. Edited by Wyszynski DF, Graham TP, Correa-Villasenor A. Oxford University Press, New York, 2010;p. 401-14.

Jamieson DJ, Honein MA, Rasmussen SA, Williams JL, Swerdlow DL, Biggerstaff MS, Lindstrom S, Louie JK, Christ CM, Bohm SR, Fonseca VP, Ritger KA, Kuhles DJ, Eggers P, Bruce H, Davidson HA, Lutterloh E, Harris ML, Burke C, Cocoros N, Finelli L, MacFarlane KF, Shu B, Olsen SJ; Novel Influenza A (H1N1) Pregnancy Working Group. H1N1 2009 influenza virus infection during pregnancy in the USA. Lancet. 2009;374(9688):451-8.

Jenkins MM, Reed-Gross E, Rasmussen SA, Barfield WD, Prue CE, Gallagher ML, Honein MA. Maternal attitudes toward DNA collection for gene-environment studies: a qualitative research study. Am J Med Genet A. 2009;149A(11):2378-86.

Jin L, Yeung LF, Cogswell ME, Ye R, Berry RJ, Liu J, Hu DJ, Zhu L. Prevalence of anaemia among pregnant women in south-east China, 1993-2005. Public Health Nutr. 2010;13(10):1511-8.

Johnson CY, Honein MA, Hobbs CA, Rasmussen SA; National Birth Defects Prevention Study. Prenatal diagnosis of orofacial clefts, National Birth Defects Prevention Study, 1998-2004. Prenat Diagn. 2009;29(9):833-9.

Johnson CY, Rasmussen SA. Non-genetic risk factors for holoprosencephaly. Am J Med Genet C Semin Med Genet.2010;154C(1):73-85.

Kitzmiller JL, Wallerstein R, Correa A, Kwan S. Preconception care for women with diabetes and prevention of major congenital malformations. Birth Defects Res A Clin Mol Teratol. 2010;88(10):791-803.

Lin AE, Rasmussen SA, Scheuerle A, Stevenson RE. Clinical geneticists in birth defects surveillance and epidemiology research programs: past, present and future roles. Birth Defects Res A Clin Mol Teratol. 2009;85(1):69-75.

Louie JK, Acosta M, Jamieson DJ, Honein MA; the California Pandemic (H1N1) Working Group. Severe 2009 H1N1 Influenza in Pregnant and Postpartum Women in California. N Engl J Med. 2010;362(1):27-35.

Louie JK, Jamieson DJ, Rasmussen SA. 2009 pandemic influenza A (H1N1) virus infection in postpartum women in California. Am J Obstet Gynecol. 2010;204(2):144.e1-6.

MacLehose RF, Olshan AF, Herring AH, Honein MA, Shaw GM, Romitti PA; National Birth Defects Prevention Study. Bayesian methods for correcting misclassification: an example from birth defects epidemiology. Epidemiology. 2009;20(1):27-35.

McLean E, Cogswell M, Egli I, Wojdyla D, de Benoist B. Worldwide Prevalence of Anaemia, WHO Vitamin and Mineral Nutrition Information System, 1993-2005 Public Health Nutrition. 2009;12:444-54.

Mei JV, Li L, Rasmussen SA, Collier S, Frias JL, Honein MA, Shaw GM, Lorey F, Meyer R, Chaing S, Canfield MA, Jones J, Hannon WH. (2010). Effect of specimen storage conditions on newborn

dried blood spots used to assess Toxoplasma gondii Immunoglobulin M (IgM). Clin Chim Acta. 2010;412(5-6):455-9.

Miller A, Siffel C, Correa A. Residential mobility during pregnancy: patterns and correlates. Matern Child Health J. 2010;14(4):625-34.

Miller A, Siffel C, Lu C, Riehle-Colarusso T, Frías JL, Correa A. Long-term survival of infants with atrioventricular septal defects. J Pediatr. 2010;156(6):994-1000.

Miller EA, Manning SE, Rasmussen SA, Reefhuis J, Honein MA; National Birth Defects Prevention Study. Maternal exposure to tobacco smoke, alcohol and caffeine, and risk of anorectal atresia: National Birth Defects Prevention Study 1997-2003. Paediatr Perinat Epidemiol. 2009;23(1):9-17.

Miller EA, Rasmussen SA, Siega-Riz AM, Frías JL, Honein MA, and the National Birth Defects Prevention Study. Risk factors for non-syndromic holoprosencephaly. Am J Med Genet C Semin Med Genet. 2010;154C(1):62-72.

Mokdad AH, Annest JL, Ikeda RM, Mai CT. Public Health Surveillance for Chronic Diseases, Injuries, and Birth Defects. Principles and Practice of Public Health Surveillance, Third Edition. Edited by Lee LM, Teutsch SM, Thacker SB, St. Louis ME. Oxford University Press, New York. 2010;p. 255-74.

Morgan MA, Cragan JD, Goldenberg RL, Rasmussen SA, Schulkin J. Management of prescription and nonprescription drug use during pregnancy. J Matern Fetal Neonatal Med. 2010;23(8):813-9.

Morgan MA, Cragan JD, Goldenberg RL, Rasmussen SA, Schulkin J.Obstetrician-Gynecologist Knowledge of and Access to Information About the Risks of Medication Use During Pregnancy. J Matern Fetal Neonatal Med. 2010;23(10):1143-50.

Oster ME, Riehle-Colarusso T, Correa A. An update on cardiovascular malformations in congenital rubella syndrome. Birth Defects Res A Clin Mol Teratol. 2009;88(1):1-8.

Pace JE, Shin M, Rasmussen, SA. Understanding Attitudes toward Persons with Down Syndrome. Am J Med Genet A 152A(9):2185-92.

Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, Anderson P, Mason CA, Collins JS, Kirby RS, and Correa A for the National Birth Defects Prevention Network. Updated National Birth Prevalence Estimates for Selected Birth Defects in the United States, 2004-2006. Birth Defects Res A Clin Mol Teratol. 2010;88(12):1008-16.

Parker SE, Mai CT, Strickland MJ, Olney RS, Rickard R, Marengo L, Wang Y, Hashmi SS, Meyer RE; National Birth Defects Prevention Network. Multistate study of the epidemiology of clubfoot. Birth Defects Res A Clin Mol Teratol. 2009;85(11):897-904.

Petrini JR, Broussard CS, Gilboa SM, Lee KA, Oster M, Honein MA. Racial differences in neonatal mortality attributable to congenital heart defects by gestational age – United States, 2003–2006. MMWR Morb Mortal Wkly Rep. 2010;59(37):1208-11.

Power ML, Cogswell ME, Schulkin J. US obstetrician-gynaecologist's prevention and management of obesity in pregnancy. J Obstet Gynaecol. 2009;29(5):373-7.

Prakalapakorn SG, Rasmussen SA, Lambert SR, Honein MA, and the National Birth Defects Prevention Study. Assessment of risk factors for infantile cataracts using a case-control study, National Birth Defects Prevention Study, 2000-2004. Ophthalmology. 2010;117(8):1500-5.

Ramadhani T, Short V, Canfield MA, Waller DK, Correa A, Royle M, Scheuerle A; National Birth Defects Prevention Study (NBDPS). Are birth defects among Hispanics related to maternal nativity or number of years lived in the United States? Birth Defects Res A Clin Mol Teratol. 2009;85(9):755-63.

Rasmussen SA, Chambers C, Hales B. 50 years of the Teratology Society: Honoring past accomplishments and a view to a promising future. Birth Defects Res Part A Clin Mol Teratol. 2010;88(10):763-5.

Rasmussen SA, Erickson JD, Reef SE, Ross DS. Teratology: from science to birth defects prevention. Birth Defects Res A Clin Mol Teratol. 2009;85(1):82-92.

Rasmussen SA, Galuska DA. Prepregnancy obesity and birth defects: what's next? Am J Clin Nutr. 2010;91(6):1539-40.

Rasmussen SA, Jamieson DJ, Macfarlane K, Cragan JD, Williams J, Henderson Z. Pandemic Influenza and Pregnancy Working Group. Pandemic influenza and pregnant women: summary of a meeting of experts. Am J Public Health. 2009;99 Suppl 2:S248-54.

Rasmussen SA, Shaw GM. How do Epidemiologic

Studies Contribute to the Identification of Teratogenic Exposures? Teratology Primer. 2nd edition. Edited by Hales B, Scialli A, Tassinari M. p. 30-32.

Rasmussen SA. Does Maternal Diabetes or Obesity Increase the Risk of Having a Child with a Birth Defect. Teratology Primer. 2nd edition. Edited by Hales B, Scialli A, Tassinari M. Teratology Society (online), 2010;p. 75-76.

Reefhuis J, Honein MA, Schieve L, Correa A, Hobbs CA, Rasmussen SA, and the National Birth Defects Prevention Study. Reply: ART and major structural birth defects in the USA. Hum Reprod. 2009;24(7):1766.

Reefhuis J, Honein MA, Schieve LA, Correa A, Hobbs CA, Rasmussen SA; National Birth Defects Prevention Study. Assisted reproductive technology and major structural birth defects in the United States. Hum Reprod. 2009;24(2):360-6.

Reefhuis J, Honein MA, Schieve LA, Rasmussen SA, and the National Birth Defects Prevention Study. Use of clomiphene citrate and birth defects, National Birth Defects Prevention Study, 1997-2005. Hum Reprod. 2010;26(2):451-7.

Reefhuis J, Whitney CG, Mann EA. A Public Health Perspective on Cochlear Implants and Meningitis in Children. Otol Neurotol. 2010;31(8):1329-30.

Robitaille J, Hamner HC, Cogswell ME, Yang Q. Does the MTHFR 677C-->T variant affect the Recommended Dietary Allowance for folate in the US population? Am J Clin Nutr. 2009;89(4):1269-73.

Ross DS, Rasmussen SA, Cannon MJ, Anderson B, Kilker K, Tumpey A, Schulkin J, Jones JL. Obstetrician-gynecologists' knowledge, attitudes, and practices regarding prevention of infections in pregnancy. J Women's Health . 2009;1(8):1187-93.

Sadler TW, Rasmussen SA. Examining the evidence for vascular pathogenesis of selected birth defects. Am J Med Genet A. 2010;152A(10):2426-36.

Sanchez-Lara PA, Carmichael SL, Graham JM, Lammer EJ, Shaw GM, Ma C, Rasmussen SA, and the National Birth Defects Prevention Study. (2010). Fetal constraint as a potential risk factor for craniosynostosis. Am J Med Genet A. 152A:394-400.

Schieve LA, Boulet SL, Boyle C, Rasmussen SA, Schendel D. Health of children 3 to 17 years of age with Down syndrome in the 1997-2005 national health interview survey. Pediatrics. 2009;123(2):e253-60.

Shin M, Besser LM, Kucik JE, Lu C, Siffel C, Correa A; Congenital Anomaly Multistate Prevalence and Survival Collaborative. Prevalence of Down syndrome among children and adolescents in 10 regions of the United States. Pediatrics. 2009;124(6):1565-71.

Shin M, Besser LM, Siffel C, Kucik, JE, Shaw GM, Lu C, Correa A and the CAMPS collaborative. Prevalence of children and adolescents with spina bifida in 10 regions of the United States. Pediatrics.2010;126(2):274-9.

Shin M, Siffel C, Correa A. Survival of Children With Mosaic Down Syndrome. Am J Med Genet A. 2010;152A(3):800-1.

Siston AM, Rasmussen SA, Honein MA, Fry AM, Seib K, Callaghan WM, Louie J, Doyle TJ, Crockett M, Lynfield R, Moore Z, Wiedeman C, Anand M, Tabony L, Nielsen CF, Waller K, Page S, Thompson JM, Avery C, Springs CB, Jones T, Williams JL, Newsome K, Finelli L, Jamieson DJ; Pandemic H1N1 Influenza in Pregnancy Working Group. Pandemic 2009 Influenza A(H1N1) Virus Illness among Pregnant Women in the United States. JAMA. 2010;303(15):1517-25.

Steenland K, Tinker SC, Frisbee S, Ducatman A, Vaccarino V. Association of Perfluorooctanoic Acid and Perfluorooctane Sulfonate with Serum Lipids Among Adults Living Near a Chemical Plant. Am J Epidemiol. 2009;170(10):1268-78.

Steenland K, Tinker SC, Shankar A, Ducatman A. Association of perfluorooctanoic acid (PFOA) and perfluorooctanesulfonate (PFOS) with uric acid among adults with elevated community exposure to PFOA. Environ Health Perspect. 2010;118(2):229-33.

Strickland MJ, Klein M, Correa A, Reller MD, Mahle WT, Riehle-Colarusso TJ, Botto LD, Flanders WD, Mulholland JA, Siffel C, Marcus M, Tolbert PE. Ambient air pollution and cardiovascular malformations in Atlanta, Georgia, 1986-2003. Am J Epidemiol. 2009;169(8):1004-14.

Tessema J, Jefferds ME, Cogswell M, Carlton E. Motivators and barriers to prenatal supplement use among minority women in the United States. J Am Diet Assoc. 2009;109(1):102-8.

Timperio CG, Humbaugh K, Riggs M, Thoroughman D, Barrios L, Copeland D, Waller A, Denniston M, Beavers S, Broussard C .Impact of Seasonal

Influenza-Related School closures on families-Southeastern Kentucky, Feb 2008. MMWR Morb Mortal Wkly Rep.2009;58(50):1405-9.

Tinker SC, Cogswell ME, Devine O, Berry RJ. Folic acid intake among U.S. women aged 15-44 years, National Health and Nutrition Examination Survey, 2003-2006. Am J Prev Med. 2010;38(5):534-42.

Tinker SC, Moe CL, Klein M, Flanders WD, Uber J, Amirtharajah A, Singer P, Tolbert PE. Drinking water residence time in distribution system networks and emergency department visits for gastrointestinal illness in metro Atlanta, Georgia. Journal of Water and Health. 2009;7(2):332-43.

Tinker SC, Moe CL, Klein M, Flanders WD, Uber J, Amirtharajah A, Singer P, Tolbert PE. Drinking water turbidity and emergency department visits for gastrointestinal illness in Atlanta, 1993 – 2004. J Expo Sci Environ Epidemiol. 2010;20(1):19-28.

Tinker SC, Reefhuis J, Dellinger AM, and Jamieson DJ. Epidemiology of maternal injuries during pregnancy in a population-based study, 1997-2005. J Womens Health (Larchmt). 2010;19(12):2211-8.

van Gelder MM, Reefhuis J, Caton AR, Werler MM, Druschel CM, Roeleveld N; National Birth Defects Prevention Study. Maternal periconceptional illicit drug use and the risk of congenital malformations. Epidemiology. 2009;20(1):60-6.

van Gelder MM, Reefhuis J, Caton AR, Werler MM, Druschel CM, Roeleveld N; the National Birth Defects Prevention Study. Characteristics of pregnant illicit drug users and associations between cannabis use and perinatal outcome in a population-based study. Drug Alcohol Depend. 2010;109(1-3):243-7.

Wang Y, O'Leary LA, Rickard RS, Mason CA for the National Birth Defects Prevention Network. Geocoding Capacity of Birth Defects Surveillance Programs: Results from the National Birth Defects Prevention Network Geocoding Survey. Journal of Registry Management. 2010;37(1):22-6.

Werler MM, Mitchell AA, Moore CA, Honein MA; National Birth Defects Prevention Study. Is there epidemiologic evidence to support vascular disruption as a pathogenesis of gastroschisis? Am J Med Genet A. 2009;149A(7):1399-406.

Yang Q, Cogswell ME, Hamner HC, Carriquiry A, Bailey LB, Pfeiffer CM, Berry RJ. Folic acid source, usual intake, and folate and vitamin B-12 status in US adults, 2003-2006. Am J Clin Nutr. 2010;91(1):64-72.

Yeung LF, Cogswell ME, Carriquiry AL, Bailey LB, Pfeiffer CM, Berry RJ. Contributions of enriched cereal-grain products, ready-to-eat cereals, and supplements to folic acid and vitamin B-12 usual intake and folate and vitamin B-12 status in US children: National Health and Nutrition Examination Survey, 2003-2006. Am J Clin Nutr. 2010;93(1):172-85.

USA, Texas: TBDR

Published Abstracts/Presentations [Texas Birth Defects Registry (TBDR) Data Only]

Au KS, Ashley-Koch A, Northrup H. Epidemiologic and genetic aspects of spina bifida and other neural tube defects. *Dev Disabil Res Rev*. 2010;16(1):6-15. Review.

Blanton SH, Burt A, Stal S, Mulliken JB, Garcia E, Hecht JT. Family-based study shows heterogeneity of a susceptibility locus on chromosome 8q24 for nonsyndromic cleft lip and palate. *Birth Defects Res A Clin Mol Teratol*. 2010 Apr;88(4):256-9.

Chapkin RS, Kamen BA, Callaway ES, Davidson LA, George NI, Wang N, Lupton JR, Finnell RH. Use of a novel genetic mouse model to investigate the role of folate in colitis-associated colon cancer. *J Nutr Biochem*. 2009 Aug;20(8):649-55.

Ester AR, Weymouth KS, Burt A, Wise CA, Scott A, Gurnett CA, Dobbs MB, Blanton SH, Hecht JT. Altered transmission of HOX and apoptotic SNPs identify a potential common pathway for clubfoot. *Am J Med Genet A*. 2009 Dec;149A(12):2745-52.

Gray RS, Abitua PB, Wlodarczyk BJ, Szabo-Rogers HL, Blanchard O, Lee I, Weiss GS, Liu KJ, arcotte EM, Wallingford JB, Finnell RH. The planar cell polarity effector Fuz is essential for targeted membrane trafficking, ciliogenesis and mouse embryonic development. *Nat Cell Biol*. 2009 Oct;11(10):1225-32.

Hill DS, Wlodarczyk BJ, Mitchell LE, Finnell RH. Arsenate-induced maternal glucose intolerance and neural tube defects in a mouse model. *Toxicol Appl Pharmacol*. 2009 Aug 15;239(1):29-36.

Lupo PJ, Symanski E, Waller DK, Chan W, Canfield MA, Langlois PH, Mitchell LE; and the National Birth Defects Prevention Study. Polytomous logistic regression as a tool for exploring heterogeneity across birth defect subtypes: an example using anencephaly and spina bifida. *Birth Defects Res A Clin Mol Teratol*. 2010 Aug;88(8):701-5.

Martinez CA, Northrup H, Lin JI, Morrison AC, Fletcher

JM, Tyerman GH, Au KS. Genetic association study of putative functional single nucleotide polymorphisms of genes in folate metabolism and spina bifida. *Am J Obstet Gynecol*. 2009 Oct;201(4):394.e1-11.

Mitchell LE, Long J, Garbarini J, Paluru P, Goldmuntz E. Variants of folate metabolism genes and risk of left-sided cardiac defects. *Birth Defects Res A Clin Mol Teratol*. 2010 Jan;88(1):48-53.

O'Byrne MR, Au KS, Morrison AC, Lin JI, Fletcher JM, Ostermaier KK, Tyerman GH, Doebel S, Northrup H. Association of folate receptor (FOLR1, FOLR2, FOLR3) and reduced folate carrier (SLC19A1) genes with meningomyelocele. *Birth Defects Res A Clin Mol Teratol.* 2010 Aug;88(8):689-94.

National Birth Defects Prevention Study (NBDPS) Published/In Press Manuscripts [NBDPS Pooled Data Only]

Bitsko RH, Reefhuis J, Louik C, Werler M, Feldkamp ML, Waller DK, Frias J, Honein M. Periconceptional use of weight loss products including ephedra and the association with birth defects. *Birth Defects Res A Clin Mol Teratol*, 2008 Jun 13. [Epub ahead of print]

Brender JD, Kelley KE, Werler MM, Langlois PH, Suarez L, Canfield MA; National Birth Defects Prevention Study. Prevalence and patterns of nitrosatable drug use among U.S. women during early pregnancy. *Birth Defects Res A Clin Mol Teratol*, 2011. [In Press]

Brender JD, Werler MM, Kelley KE, Vuong AM, Shinde MU, Shinde QZ, Huber JC, Sharkey JR, Griesenbeck JS, Romitti PA, Langlois PH, Suarez L, Canfield MA, and the National Birth Defects Prevention Study. Nitrosatable drug exposure during early pregnancy and neural tube defects in offspring. *AmJ Epidemiology*, 2011. [In Press]

Browne ML, Rasmussen SA, Hoyt AT, Waller DK, Druschel CM, Caton AR, Canfield MA, Lin AE, Carmichael SL, Romitti PA, and the National Birth Defects Prevention Study. Maternal thyroid disease, thyroid medication use and selected birth defects in the National Birth Defects Prevention Study. *Birth Defects Res A Clin Mol Teratol*, 2009; 85(7): 621 – 628.

Canfield MA, Ramadhani TA, Shaw GM, Waller DK, Carmichael SL, Mosley B, Royle MH, Olney RS, and the National Birth Defects Prevention Study. Anencephaly and spina bifida among Hispanics: Maternal, socio-demographic, and acculturation factors in the National Birth Defects Prevention Study. *Birth Defects Res A Clin Mol Teratol*, 2009; 85(7): 637 – 646.

Ethen MK, Ramadhani TA, Scheuerle AE, Canfield MA, Wyszynski DF, Druschel CM, and Romitti PA, and the National Birth Defects Prevention Study. Alcohol consumption by women before and during pregnancy. *Matern Child Health J,* 2009; 13:274-285.

Gallaway MS, Waller DK, Canfield MA, Scheuerle A and the National Birth Defects Prevention Study. The association between use of spermicides or male condoms and major structural birth defects. *Contraception* 2009; 80(5):422 – 429.

Gilboa SM, Correa A, Botto LD, Rasmussen SA, Waller DK, Hobbs CA, Cleves MA, Riehle-Colarusso TJ and the National Birth Defects Prevention Study. Association between pre-pregnancy body mass index and congenital heart defects. *Am J Obstet Gynecol,* 2010; 202(1):51e1-51.e10.

Grisenbeck JS, Brender JD, Sharkey JR, Steck Michelle D, Huber JC, Rene AA, McDonald TJ, Romitti PA, Canfield MA, Langlois PH, Suarez L. Maternal characteristics associated with the dietary intake of nitrates, nitrites, and nitrosamines in U.S. women of child-bearing age: a cross-sectional study. *J Environ Health* 2010; 9:10-23.

Griesenbeck JS, Steck MD, Huber JC, Sharkey JR, Rene AA, Brender JD. Development of estimates of dietary nitrates, nitrites, and nitrosamines for use with the short willet food frequency questionnaire. *Nutrition Journal*, 2009; 8:16.

Duong H, Hashmi SS, Ramadhani T, Canfield MA, Scheuerle A, Waller DK; National Birth Defects Prevention Study. Maternal use of hot tub and major structural birth defects. *Birth Defects Res A Clin Mol Teratol*, 2011. [In Press]

Hashmi SS, Gallaway MS, Waller DK, Langlois P, Werler M, Rasmussen S, Hecht JR. Maternal fever during early pregnancy and the risk of oral clefts. *Birth Defects Res A Clin Mol Teratol*, 2010; 88(3): 186 – 194.

Langlois PH, Ramadhani T, Royle M, Robbins JM, Scheuerle AE, Wyzynski DF, and the National Birth Defects Prevention Study. Birth defects and military service since 1990. *Military Medicine*, 2009; 174(2), 170-176.

Lupo PJ, Symanski E, Waller DK, Chan W, Canfield MA, Langlois PH, Mitchell LE, and the National Birth Defects Prevention Study. Polytomous logistic regression as a tool for exploring heterogeneity

across birth defect subtypes: An example using anencephaly and spina bifida. *Birth Defects Res A Clin Mol Teratol*, 2010; 88(8):701-705.

Ma C, Carmichael SL, Scheuerle AE, Canfield MA, Shaw GM, and the National Birth Defects Prevention Study. Association of microtia with maternal obesity and periconceptional folic acid use. *Birth Def Res A Clin Mol Teratol*, 2010; 152A(11): 2756-2761.

Miller EA, Manning SE, Rasmussen SA, Reefhuis J, Honein MA, The National Birth Defects Prevention Study. Maternal exposure to tobacco smoke, alcohol and caffeine and risk of anorectal atresia — National Birth Defects Prevention Study 1997-2003. *Paediatric and Perinatal Epidemiology*, 2009; 23(1):9-17.

Miller EA, Rasmussen SA, Siega-Riz AM, Frías JL, Honein MA, The National Birth Defects Prevention Study. Risk factors for non-syndromic holoprosencephaly in the National Birth Defects Prevention Study. *AM J Med Genet C Semin Med Genet,* 2010; 154C(1):62-72.

Mosley BS, Cleves MA, Siega-Riz AM, Shaw GM, Canfield MA, Waller DK, Werler MM, Hobbs CA, and the National Birth Defects Prevention Study. Neural tube defects and maternal folate intake among pregnancies conceived after folic acid fortification in the United States. *Am J Epidemiol,* 2009; 169(1):9-17.

Ramadhani T, Canfield MA, Farag NH, Royle M, Scheuerle A, Waller DK, Correa A; National Birth Defects Prevention Study. Do Foreign- and U.S.-born mothers across racial/ethnic groups have a similar risk profile for selected sociodemographic and periconceptional factors? *Birth Defects Res A Clin Mol Teratol*, 2011. [In Press]

Ramadhani TR, Short V, Canfield MA, Waller DK, Kim Waller, Correa A, Royle MH, Scheuerle A, and the National Birth Defects Prevention Study (NBDPS). Are birth defects among Hispanics related to maternal country of nativity or maternal number of years lived in the United States? *Birth Defects Res A Clin Mol Teratol*, 2009; 85(9): 755–763.

Suarez L, Canfield MA, Ramadhani T, Brender J, Felkner M, Romitti P, Sun L, and the National Birth Defects Prevention Study. Maternal smoking, passive tobacco smoke, and neural tube defects. *Birth Defects Res A Clin Mol Teratol,* 2011; 91:29-33.

Waller DK, Gallaway MS, Lockwood GT, Ramadhani TA, Canfield MA, Scheuerle A, Hernandez-Diaz S, Louik C, Correa A, and the National Birth Defects Prevention Study. Use of oral contraceptives in pregnancy and major structural birth defects in offspring. *Epidemiology*, 2009; 21(2): 232 – 239.

National Birth Defects Prevention Study (NBDPS) Published Abstracts/Presentation [NBDPS Pooled Data Only]

Agopian AJ, Canfield MA, Olney RS, Lupo PJ, Ramadhani T, Mitchell LE, Shaw GM, Moore CA, and the National Birth Defects Prevention Study. Maternal race/ethnicity and sub-phenotypes of spina bifida in the National Birth Defects Prevention Study (NBDPS). Presented as poster at the *24th Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research*. June 20-21, 2011, Montreal, Quebec, Canada.

Browne ML, Caton AR, Rasmussen SA, Hoyt AT, Druschel CM, Lin AE, Waller DK, Canfield MA, Romitti PA. Maternal thyroid disease and cardiovascular malformations in the National Birth Defects Prevention Study. Presented at the *48th Annual Meeting of the Teratology*. June 28–July 2, 2008, Monterey, CA.

Browne ML, Caton AR, Rasmussen SA, Hoyt AT, Druschel CM, Waller DK, Canfield MA, Romitti PA, Carmichael SL. Maternal thyroid disease and selected anomalies in the National Birth Defects Prevention Study. Presented at the *48th Annual Meeting of the Teratology*. June 28–July 2, 2008, Monterey, CA.

Browne ML, Caton AR, Rasmussen SA, Druschel CM, Lin AE, Canfield MA, Romitti PA, Hoyt AT, and the National Birth Defects Prevention Study. Maternal thyroid disease and cardiovascular malformations in the National Birth Defects Prevention Study. Poster presented at the *11th Annual Meeting of the National Birth Defects Prevention Network*. February 2008, Washington, D.C.

Canfield MA. National Birth Defects Prevention Study: Race, Ethnicity, Nativity and Acculturation: Recent Findings and Ongoing Projects. Presented in a session on the National Birth Defects Prevention Study at the *13th Annual Meeting of the National Birth Defects Prevention Network*. March 8-10, 2010, Washington, DC. [Invited Speaker]

Canfield MA, Olney RS, Moore C, Ramadhani T, Lupo PJ, Shaw GM, Mitchell LE; National Birth Defects Prevention Study. Clinical Subtypes of Spina Bifida by Maternal Race/Ethnicity in the National Birth Defects Prevention Study. Oral presentation at *Sixth International Neural Tube Defects Conference*. September 12-15, 2009, Burlington, VT.

Canfield MA, Ramadhani TA, Shaw GM, Carmichael SL, Waller DK, Mosley BS, Royle MH, Olney RS, and the National Birth Defects Prevention Study. Anencephaly and Spina Bifida among Hispanics: Acculturation Factors in the National Birth Defects Prevention Study. Oral presentation at the *Annual Meeting of the National Centers for Birth Defects Research and Prevention*. January 2009, Atlanta, GA.

Canfield MA, Ramadhani TA, Shaw GM, Carmichael SL, Waller DK, Mosley BS, Royle MH, Olney RS, and the National Birth Defects Prevention Study. Anencephaly and Spina Bifida among Hispanics: Acculturation Factors in the National Birth Defects Prevention Study. Poster presented at the *Annual Meeting of the National Birth Defects Prevention Network*. February 2009, Nashville, TN.

Canfield MA, Ramadhani T, Shaw GM, Waller DK, Carmichael SL, Mosley B, Olney RS, and the National Birth Defects Prevention Study. Are less acculturated Hispanic parents at higher risk for having offspring with neural tube defects? Poster presented at the *Texas Birth Defects Research Symposium*. October 2008, Lubbock, TX.

Canfield MA, Ramadhani T, Shaw GM, Waller DK, Carmichael SL, Mosley B, Olney RS, and the National Birth Defects Prevention Study. Are offspring of less acculturated Hispanic parents at higher risk for spina bifida and anencephaly? Poster presented at the *41st Annual Society for Epidemiologic Research Meeting*. June 2008, Chicago, Illinois.

Canfield MA, Ramadhani T, Shaw GM, Waller DK, Carmichael SL, Mosley B, Olney RS, and the National Birth Defects Prevention Study. Are offspring of less acculturated Hispanic parents at higher risk for spina bifida and anencephaly? Poster presented at the *Annual Meeting for the Society for Pediatric Epidemiologic Research*. June 2008, Chicago, Illinois.

Canfield MA, Shaw G, Ramadhani T, Waller K, Mosley B, Carmichael S, Royle M, Olney R. Folic acid and NTDs in Hispanics and Whites: National Birth Defects Prevention Study, 1999-2003. Presented at the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention for the National Birth Defects Prevention Study. August 2007, Atlanta, GA. (Invited Speaker).

Canfield MA, Ramadhani T, Shaw GS, Mosely B, Waller DK, Carmichael SC, Olney R, Royle M. Periconceptional folic acid and neural tube defects in Hispanics and non-Hispanic whites. Presented at the *Annual Meeting of the National Centers for Birth Defects Research and Prevention*. November 2006, Atlanta, GA.

Carmichael SL, Shaw GM, Yang W, Laurent C, Herring A, Royle M, Canfield M. Correlates of intake of folic acid-containing supplements among pregnant women. *Annual Meeting of the National Birth Defects Prevention Network*. January 2005, Scottsdale, AZ.

Case A, Royle M, Scheuerle A, Carmichael S, Mitchell L. What Do You Think Causes Birth Defects? A Content Analysis of Mothers' Responses in the National Birth Defects Prevention Program Study. *16th Annual Maternal and Child Health Epidemiology Conference*. December 15-17, 2010, San Antonio, TX.

Collier S, Dollard S, Mei J, Honein M, Hannon WH, Frias JL, Shaw GM, Meyer R, Chaing S, Canfield MA, Rasmussen SA. The contribution of CMV to hydrocephalus: A pilot study using newborn dried blood spots. Presented at the *Congenital Cytomegalovirus Conference*. November 2008, Atlanta, GA

Ethen MK, Ramadhani TA, Scheuerle AE, Canfield MA, Wyszynski DF, Druschel CM, and Romitti PA. Alcohol Consumption by Women Before and During Pregnancy. Poster presented at the *9th Annual Meeting of the National Birth Defects Prevention Network*. January 2006, Arlington, Virginia. (AWARD WINNER)

Ethen MK, Ramadhani TA, Scheuerle AE, Canfield MA, Wyszynski DF, Druschel CM, Romitti PA. Alcohol Consumption by Women Before and During Pregnancy. Presented at the *Texas Birth Defects Research Symposium*. April 2006, Austin, Texas.

Ethen MK, Ramadhani TA, Scheuerle AE, Canfield MA, Wyszynski DF, Druschel CM, Romitti PA, and the National Birth Defects Prevention Study. Alcohol Consumption by Women Before and During Pregnancy. Poster presented at the *Texas Birth Defects Research Symposium*. October 2008, Lubbock, TX.

Ethen MK, Ramadhani TA, Scheuerle AE, Canfield MA, Wyszynski DF, Druschel CM, Romitti PA. Alcohol Consumption by Women Before and During Pregnancy. Presentation by Mark Canfield, Ph.D. to the *Centers for Birth Defects Research and Prevention Annual Meeting*. November 2005, Washington, D.C.

Hashmi SS, Waller DK, Langlois PH, Rasmussen

SA and Hecht JT. Maternal Hyperthermia and Orofacial Clefting – Preliminary Results from the National Birth Defects Prevention Study. Presented at the *Centers for Birth Defects Research and Prevention Annual Meeting*. November 2007, Atlanta, Georgia.

Hobbs CA, Mosley BS, Shaw GS, Siega-Riz AM, Waller DK, Canfield M, Zhao W, Cleves MA and the National Birth Defects Prevention Study. Neural tube defects and periconceptional intake of micronutrients following mandatory folic acid fortification. Presented at the *National Birth Defects and Prevention Network Annual Meeting*. January 2006, Arlington, Virginia.

Huber, Jr, Q Zheng, J Sharkey, J Brender, A Vuong, M Shinde, L Suarez, P Langlois, M Canfield, P Romitti, S Malik, and the National Birth Defects Prevention Study. Dietary Nitrates, Nitrites and Nitrosatable Compounds and Neural Tube Defects, Oral Clefts and Limb Deficiencies. Poster presented at the 24th *Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research (SPER)*. June 20-21, 2011, Montreal, Quebec, Canada.

Huber J, Zheng Q, Sharkey J, Brender J, Vuong A, Shinde M, Suarez L, Langlois P, Canfield M, Romitti P, Malik S, National Birth Defects Prevention Study. Dietary Nitrates, Nitrites and Nitrosatable Compounds and Neural Tube Defects, Oral Clefts and Limb Malformations. Poster presented at the *3rd North American Congress of Epidemiology Conference/Annual Meeting of the Society for Epidemiologic Research (SER)*. June 22-24, 2011, Montreal, Quebec, Canada.

Langlois P, Wyszynski D, Royle M, Robbins J, Scheuerle A, del Junco D. Utility of retaining questions on parental military service. Poster presented at the *Annual Meeting of the Centers for Birth Defects Research and Prevention*. November 2004.

Lupo PJ, Mitchell LE, Canfield MA, Shaw GM, Waller DK, Correa A, Olshan AF, Finnell RH, Zhu H. Glucose homeostasis genes and the risk of neural tube defects in the National Birth Defects Prevention Study. Poster presented at the 24th *Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research (SPER)*. June 2011, Montreal, Quebec, Canada.

Lupo PJ, Symanski E, Chan W, Waller DK, Canfield MA, Langlois PH, Mitchell LE; National Birth Defects Prevention Study. An Evaluation of the Validity of Using Composite Endpoints for Neural Tube Defects in the National Birth Defects Prevention Study. Oral presentation at *Sixth International Neural Tube Defects Conference*. September 12-15, 2009, Burlington, VT.

Ramadhani T. The association between pregnancy-related risk factors and nativity status, by race/ethnicity. *16th Annual Maternal and Child Health Epidemiology Conference*. December 15-17, 2010, San Antonio, TX.

Ramadhani T, Short V, Canfield MA, Waller DK, Royle M, Correa A, Scheuerle A and the National Birth Defects Prevention Study Birth defects in Non-Hispanic Blacks: Are they Related to Mothers' Nativity? Presented as poster at the *Annual Meeting of the National Centers for Birth Defects Research and Prevention*. January 26-27, 2010, Decatur, GA.

Ramadhani T, Canfield MA, Waller DK, Royle M, Correa A, Scheuerle, and the National Birth Defects Prevention Study. Birth Defects in Non-Hispanic Whites: Are They Related to Mothers' Nativity? Poster presented at the *Annual Meeting of the National Centers for Birth Defects Research and Prevention*. January 26-27, 2010, Decatur, GA.

Ramadhani T, Canfield MA, Waller K, Royle M, Correa A, Angela Scheuerle and the National Birth Defects Prevention Study. Variation in pregnancy-related risk behaviors and maternal conditions among United States and foreign born mothers by race/ethnicity. Poster presented at the *Texas Birth Defects Research Symposium*. October 2008, Lubbock, TX.

Ramadhani T, Short V, Canfield MA, Waller DK, Correa A, Royle M, Scheuerle A, and the National Birth Defects Prevention Study. Birth defects in non-Hispanic blacks: Are they related to mothers' birth nativity? Poster presented at the *Texas Birth Defects Research Symposium*. October 2008, Lubbock, TX.

Ramadhani T, Short V, Canfield MA, Waller DK, Correa A, Royle M, Scheuerle A, and the National Birth Defects Prevention Study. Birth defects in non-Hispanic blacks: Are they related to mothers' birth nativity? Poster presented at the *Texas Birth Defects Research Symposium*. October 2008, Lubbock, TX.

Ramadhani T, Canfield MA, Waller DK, Royle M, Correa A, and the National Birth Defects Prevention Study. Variation in pregnancy-related risk factors among foreign- vs. US-born mothers, by race/ethnicity. Poster presented at the *Texas Birth Defects Research Symposium*. October 2008, Lubbock, TX.

Ramadhani T, Canfield MA, Waller K, Royle M, Correa A, and the National Birth Defects Prevention Study. Variation in pregnancy-related risk behaviors and maternal conditions among United States and foreign born mothers by race/ethnicity. Poster presented at the *41st Annual Society for Epidemiologic Research Meeting*. June 2008, Chicago, Illinois.

Ramadhani T, Canfield MA, Waller K, Royle M, Correa A, and the National Birth Defects Prevention Study. Variation in pregnancy-related risk behaviors and maternal conditions among United States and foreign born mothers by race/ethnicity. Poster presented at the *National Birth Defects and Prevention Network 11th Annual Meeting*. February 2008, Washington, D.C.

Ramadhani T, Short V, Canfield MA, Waller K, Royle M, Correa A, Scheuerle A, and the National Birth Defects Prevention Study. Birth defects in Hispanics: Are they related to mothers' birthplace? Poster presented at the *National Birth Defects and Prevention Network Annual Meeting*. February 2008, Washington, D.C.

Ramadhani T, Short V, Canfield MA, Waller K, Royle M, Correa A, Scheuerle A, and the National Birth Defects Prevention Study. Birth defects in Hispanics: Are they related to mothers' birthplace? Poster presented at the *Centers for Birth Defects Research and Prevention 2007 Annual Meeting*. November 2007, Atlanta, GA.

Ramadhani T, Ethen MK, Ramadhani TA, Scheuerle AE, Canfield MA, Wyszynski DF, Druschel CM, Romitti PA. Alcohol consumption by women in the U.S. before and during pregnancy. Poster presented at the *2nd International Conference on Fetal Alcohol Spectrum Disorders*. March 2007, Victoria, British Columbia, Canada.

Rasmussen SA, Yazdy M, Honein MA, Carmichael S, Canfield M. Maternal thyroid disease as a possible risk factor for craniosynostosis – National Birth Defects Prevention Study. Presented at the *Annual David Smith Dysmorphology Workshop*. September 2006, Lake Arrowhead, CA.

Rasmussen SA, Yazdy M, Honein M, Carmichael S, Canfield M, and the National Birth Defects Prevention Study. Maternal Thyroid Disease as a Possible Risk Factor for Craniosynostosis, National Birth Defects Prevention Study, 1997-2002 2002. Presented at the *Annual Meeting of the Teratology Society*. June 2006, San Diego, CA.

Reefhuis J, Honein M, Rasmussen S, Correa A, Hobbs C, Scheuerle A, Schieve L. Assisted reproductive techniques and the risk of oral clefts: Data from the National Birth Defects Prevention Study, 1997- 2000. Presented at *Teratology Society Meeting* June 26 - July 1, 2004. Vancouver, British Columbia, Canada.

Scheuerle AE, Wright D. Ethical Issues Encountered in the Establishment of the Texas Birth Defects Research Center. Poster presented at the *American College of Medical Genetics Annual Meeting*, March 9-12, 2000, Palm Springs, CA.

Waller DK, Gallaway MS, Canfield MC, Hernandez-Diaz S, Louik C. The use of hormonal contraceptives in the periconceptional period and the occurrence of structural malformations. Poster presented at the *Annual Meeting of the National Centers for Birth Defects Research and Prevention*. November 2006, Atlanta, GA.

Waller DK, Shaw GM, Rasmussen SA, Hobbs CA, Canfield MA, Siega-Riz AM, Correa A, Gallaway MS. Maternal Obesity and Birth Defects – Preliminary Results from the National Birth Defects Prevention Study. Presented at the *National Birth Defects and Prevention Network Annual Meeting*. January 2006, Arlington, Virginia.

Waller DK, Shaw GM, Rasmussen SA, Hobbs CA, Canfield MA, Siega-Riz AM, Correa A, and Gallaway MS. Maternal Obesity and Birth Defects – Preliminary Results from the National Birth Defects Prevention Study. Presented at the *National Birth Defects and Prevention Network Annual Meeting*. January 2006, Arlington, Virginia.

Waller DK, Shaw GM, Rasmussen SA, Hobbs CA, Canfield MA, Siega-Riz AM, Correa A, and Gallaway MS. Maternal Obesity and Birth Defects – Preliminary Results from the National Birth Defects Prevention Study. Presented at the *4th Canadian Congenital Anomalies Surveillance Network*. November 2005, Ottawa, Canada.

Waller DK, Shaw GM, Rasmussen SA, Hobbs CA, Canfield MA, Siega-Riz AM, Correa A, and Gallaway MS. Maternal Obesity and Birth Defects – Preliminary Results from the National Birth Defects Prevention Study. Presented at the *Texas Birth Defects Research Conference*. April 2005, Austin, Texas.

Weedn A, Mosley B, Cleves M, Waller DK, Canfield MA, Correa A, Hobbs C, and the National Birth Defects Prevention Study. Prenatal Diagnosis of Birth Defects in the National Birth Defects Prevention Study. Poster presented at the *Annual Meeting of the National Centers for Birth Defects Research and Prevention*. January 2009, Atlanta, GA.

Zhu H, Lupo PJ, Mitchell LE, Canfield MA, Shaw G, Waller K, Correa A, Olshan A Finnell RH, and the National Birth Defects Prevention Study. Maternal Diabetes/Obesity and Neural Tube Defects: The Genetic Link. Presented at the 6th *International Symposium on Diabetes & Pregnancy*. March 23-26, 2011, Salzburg, Austria.

National Birth Defects Prevention Study (NBDPS) Published/In Press Manuscripts [NBDPS Texas (Local Study) Only]- At Least Partially Funded by Centers Cooperative Agreement

Agopian A, Marengo L, Mitchell LE. Descriptive epidemiology of nonsyndromic omphalocele in Texas, 1999-2004. *Am J Med Genet A*. 2009 Oct;149A(10):2129-33.

Benjamin B, Ethen MK, Van Hook CL, Myers CA, Canfield MA. Gastroschisis prevalence in Texas 1999-2003. *Birth Defects Res A Clin Mol Teratol* 2010; 88:178-185.

Blanton SH, Henry RR, Yuan Q, Mulliken JB, Stal S, Finnell RH, Hecht JT. Folate pathway and nonsyndromic cleft lip and palate. *Birth Defects Res A Clin Mol Teratol.*, 2011 Jan;91(1):50-60. doi: 10.1002/bdra.20740. Epub 2010 Dec 1.

Brender J, Felkner M, Suarez L, Canfield MA, Henry JP. Maternal pesticide exposure and neural tube defects in Mexican Americans. *Annals of Epidemiology*, 2010; 20(1): 16-22.

Canfield MA, Langlois PH, Nguyen LM, Scheuerle AE. Epidemiologic features and clinical subgroups of anotia/microtia in Texas. *Birth Defects Res A Clin Mol Teratol. 2009;* 85(11):905-13.

Canfield MA, Marengo L, Ramadhani TA, Suarez L, Brender JD, Scheuerle A. The prevalence and predictors of anencephaly and spina bifida in Texas. *Paediatric and Perinatatal Epidemiol* 2009; 23(1):41-50.

Case AP, Colpitts LR, Langlois PH, Scheuerle AE. Prenatal diagnosis and cesarean section in a large, population-based birth defects registry. J Matern Fetal Neonatal Med, 2011. [In Press]

Case A. Prevalence and Patterns of Choanal Atresia and Choanal Stenosis among Pregnancies in Texas, 1999-2004. American Journal of Medical Genetics, 2011.

Case AP, Canfield MA. Methods for developing useful estimates of the costs associated with birth defects.-*Birth Defects Res A Clin Mol Teratol.* 2009; 85(11):920-4.

Chiang P-W, Spector E, Scheuerle A. A case of Asian Indian OCA3 patient. *Amer J Med Genet (Part A),* 2009;149(7):1578-1580.

Chiquet BT, Henry R, Burt A, Mulliken JB, Stal S, Blanton SH, Hecht JT. Nonsyndromic cleft lip and palate: CRISPLD genes and the folate gene pathway connection. Birth Defects Res A Clin Mol Teratol. 2011 Jan;91(1):44-9. doi: 10.1002/bdra.20737. Epub 2010 Nov 15.

Collins JS, Canfield MA, Pearson K, Kirby RS, Case AP, Mai CT, Major J, Mulinare J for the National Birth Defects Prevention Network. Public Health Projects for Preventing the Recurrence of Neural Tube Defects in the United States. *Birth Defects Res A Clin Mol Teratol,* 2009; 85:935 – 938.

Felkner M, Suarez L, Canfield MA, Brender JD, Sum Q. Maternal serum homocysteine and risk for neural tube defects in a Texas-Mexico border population. *Birth Defects Res A Clin Mol Teratol*, 2009; 85(6):574-581.

Fixler DE, Nembhard WN, Salemi JL, Ethen MK, Canfield MA. Mortality in first five years in infants with functional single ventricle born in Texas, 1996-2003. *Circulation,* 2010; 121: 644-650.

Graham A, Brender JD, Sharkey JR, Zhu L, Felkner M, Suarez L, Canfield MA. Dietary methionine intake and neural tube defects in Mexican-American women. *Birth Defects Res A Clin Mol Teratol*, 2010; 88:451-457.

Honein M, Kirby R, Meyer R, Xing J, Skerrette N, Yuskiv N, Marengo L, Petrini J, Davidoff M, Mai C, Druschel C, Viner-Brown S, Sever L, and the National Birth Defects Prevention Network. The association between major birth defects and preterm birth. *Maternal and Child Health Journal,* 2009; 13(2): 164 – 175.

Langlois P, Marengo L, Canfield MA. Time trends in the prevalence of birth defects in Texas 1999-2007: Real or artifactual? *Birth Defects Res A Clin Mol Teratol*, 2011. [In Press]

Langlois PH, Sheu SH, Scheuerle AE. A physician survey regarding diagnostic variability among birth defects. *American Journal of Medical Genetics Part A 152A:* 1594-1598, 2010.

Langlois PH, Scheuerle A, Horel SA, Carozza SE. Urban versus rural residence and occurrence of septal heart defects in Texas. *Birth Defects Research Part A,* 2009; 85(9): 764 – 772.

Langlois PH, Brender JD, Suarez L, Zhan FB, Mistry

JH, Scheuerle A, Moody K,. Maternal residential proximity to waste sites and industrial facilities and conotruncal heart defects in offspring. *Paediatric and Perinatal Epidemiology* 2009; 23(4): 321-331.

Lin AE, Rasmussen SA, Scheuerle A, Stevenson RE. Clinical geneticists in birth defects surveillance and epidemiology research programs: past, present and future roles. *Birth Defects Research Part A,* 2009; 85:69-75.

Lu W, Guzman AR, Yang W, Chapa CJ, Shaw GM, Greene RM, Pisano MM, Lammer EJ, Finnell RH, Zhu H. Genes encoding critical transcriptional activators for murine neural tube development and human spina bifida: A case-control study. *BMC Med Genet,* 2010; 11:141.

Luben TJ, Messer LC, Mendola P, Carozza SE, Horel SA, Langlois PH. Urban-rural residence and the occurrence of neural tube defects in Texas, 1999 – 2003. *Health & Place,* 2009; 15(2009):848-854.

Lupo PJ. Epidemiology of Ebstein's Anomaly: Prevalence and Patterns in Texas, 1999-2005. *American Journal of Medical Genetics*. 2011.

Lupo PJ, Symanski E, Waller DK, Chan W, Langlois PH, Canfield MA, Mitchell LE. Maternal exposure to ambient levels of benzene and neural tube defects among offspring, Texas, 1999-2004. *Environ Health Perspect,* 2010; 119(3):397-402.

Lupo PJ, Symanski E, Chan W, Mitchell LE, Waller DK, Canfield MA, Langlois PH. Differences in exposure assignment between conception and delivery: The impact of maternal mobility. *Paediatric and Perinatal Epidemiology* 2010; 24(2):200-208.

Mei JV, Li L, Rasmussen SA, Collier S, Frias JL, Honein MA, Shaw GM, Lorey F, Meyer R, Chaing S, Canfield MA, Jones J, Hannon WH. Effects of specimen storage conditions on newborn dried blood spots used to assess Toxoplasma gondii Immunoglobulin M (IgM). *Clin Chim Acta,* 2011; 412 (5-6):455-459.

Messer LC, Luben TJ, Mendola P, Carozza SE, Horel SA, Langlois PH. Urban-rural residence and the occurrence of cleft lip and cleft palate in Texas, 1999-2003. *Annals of Epidemiology* 20: 32-39, 2010.

Naufal Z, Zhiwen L, Zhu L, Zhou GO, McDonald T, He LY, Mitchell L, Ren A, Zhu, Finnell R, Donnelly KC. Biomarkers of exposure to combustion by-products in a human population in Shanxi, China. *J Expo Sci Environ Epidemiol.* 2010; 20(4):310-319.
Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Dimaggio A, Canfield MA. Racial/Ethnic disparities in risk of early childhood mortality among children with congenital heart defects. *Pediatrics*, 2011; 127(5):e1128-1138.

Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Canfield MA. Mortality among infants with birth defects: Joint effects of size-at-birth, gestational age and maternal race/ethnicity. *Birth Defects Res A Clin Mol Teratol*, 2010; 88:728-36.

Parks S, Canfield MA, Ramadhani TA. Importance of including all pregnancy outcomes to reduce bias in epidemiologic studies of neural tube defects — Texas, 1999–2005. *Birth Defects Res A Clin Mol Teratol*, 2011; 91:185-191.

Parker SE, Mai CT, Strickland MJ, Olney RS, Rickard R, Marengo L, Wang Y, Hashmi SS, Meyer RE, National Birth Defects Prevention Network. Multistate study of the epidemiology of clubfoot. *Birth Def Res Part A* 2009; 85(11):897-904.

Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, Anderson P, Mason CA, Collins JS, Kirby RS, and Correa A. Updated national birth prevalence estimates for selected birth defects in the United States, 2004 – 2006. *Birth Defects Res Part A: Clin Mol Teratol,* 2010; 88(12):1008-1016.

Simpson MA, Scheuerle A, Hurst J, Patton MA, Stewart H, Crosby AH. Mutations in FAM20C also identified in non-lethal osteosclerotic bone dysplasia. *Clin Genet.* 2009 Mar;75(3):271-276.

Scheuerle A, Vannappagari VX, Miller MK. Measurements of birth defect prevalence: Which is most useful as a comparator group for pharmaceutical pregnancy registries? *Birth Defects Res A Clin Mol Teratol*., 2009; 85(7): 611 – 620.

Sommer A, Blanton SH, Weymouth K, Alvarez C, Richards BS, Barnes D, Hecht JT. Smoking, the xenobiotic pathway, and clubfoot. *Birth Defects Res A Clin Mol Teratol*, 2011; 91(1):20-28.

Suarez L, Felkner M, Brender JD, Canfield MA. Dieting to lose weight and occurrence of neural tube defects in offspring of Mexican American women. *Matern Child Health J,* 2011. [In Press]
Vendola C, Canfield M, Daiger SP, Gambello M, Hashmi SS, King T, Noblin SJ, Waller DK, Hecht JT. Survival of Texas infants born with trisomies 21, 18, and 13. *Am J Med Gene Part At,* 2010; 152A:360-366.

Wen, S., Zhu, H., Lu, W., Mitchell, L.E., Shaw, G.M., Lammer, E.J. and Finnell, R.H. 2010. Planar cell

polarity pathway genes and risk for spina bifida. *Am. J. Med. Genet*., 2010; 152A(2): 299-304.

Wen S, Lu W, Zhu H, Yang W, Shaw GM, Lammer EJ, Islam A, Finnell RH. Genetic polymorphisms in the thioredoxin 2 (TXN2) gene and risk for spina bifida. *Am J Med Genet A*, 2009; 149A(2): 155 – 160.

Zhu, H., Kartiko, S. and Finnell, R.H. Importance of gene-environment interactions in the etiology of selected birth defects. *Clin Genet*, 2009; 75: 409-423.

National Birth Defects Prevention Study (NBDPS) Published Abstracts/Presentations [NBDPS Texas (Local Study) Only]- At Least Partially Funded by Centers Cooperative Agreement]

Brender J, Felkner M, Suarez L, Canfield M. Maternal pesticide exposure and neural tube defects in offspring. Presented at the *Annual Meeting of the Society for Epidemiologic Research (SER)*. June 2010, Seattle,

Canfield MA. Collaborative Projects of the State Data Committee. Presented at the *14th Annual Meeting of the National Birth Defects Prevention Network*, March 2, 2011, Orlando, FL. (Invited Speaker and Session Moderator)

Canfield MA. The Texas Experience with Birth Defects Surveillance among Military Facilities. Presented at the *14th Annual Meeting of the National Birth Defects Prevention Network*, February 28, 2011, Orlando, FL. (Invited Speaker)

Canfield M and Langlois P. Birth Defects Research in Texas. Presented at an *Epidemiology Seminar at UT School of Public Health*, Houston, February 9, 2011. (Invited Speakers)

Canfield MA. Birth Defects Program Update. Presented at the *State Program Services Committee of the March of Dimes, Texas Division*. February 7, 2011. Austin, TX. (Invited Speaker)

Canfield MA. Birth Defects Program Update. Presented at the State Public Affairs Committee of the March of Dimes, Texas Division, Jan. 9, 2011, Austin, TX. (Invited speaker)

Canfield M and Langlois P. Birth Defects in Texas and Beyond. Presented to an undergraduate course in biological sciences/genetics for Dr. Jeffrey Gross, Section of Molecular Cell and Developmental Biology, Institutes for Cell and Molecular Biology and Neuroscience, Oct. 14, 2010, The University of Texas, Austin. (Invited Speakers)

Canfield MA. The National Birth Defects Prevention Network and the State Data Committee. An Update. Presented at the *37th Annual Meeting of the International Clearinghouse for Birth Defects Surveillance and Research*, jointly held with the *42nd Annual Meeting of ECLAMC (South American Congenital Anomalies Monitoring System)*, National Academy of Medicine, Buenos Aires, Argentina, November 2, 2010. (Invited Speaker)

Canfield MA. Birth Defects Research in Texas. Presented at the *6th Biennial Texas Birth Defects Research Symposium*, Dell Medical Center, October 7, 2010, Troy, NY. (Invited Speaker)

Canfield MA. Birth Defects in Texas and Beyond: Prevalence, Patterns, and Risk Factors. Presented at the El Paso Regional Campus of the University of Texas School of Public Health, El Paso, TX, February 5, 2010. [Invited Speaker]

Canfield MA. The Texas Birth Defects Registry: Establishing, Operating, and Maintaining Funding for a Birth Defects Surveillance Program. Presented at *"The Florida Birth Defects Registry: Surveillance, Prevention and Education -Science into Action, the First 10 Years,"* January 21-22, 2010, Tampa, FL. [Invited Speaker]

Canfield MA. Birth Defects in Texas and Beyond: Prevalence, Patterns, and Risk Factors. Presented for the Bureau of Environmental and Occupational Epidemiology, New York Department of Health, September 11, 2009, Troy, NY.

Canfield MA. Birth Defects in Texas and Beyond: Prevalence, Patterns, and Risk Factors. Presented at *Statewide Training for the Birth Defects Epidemiology and Surveillance Branch*, July 5-6, 2009, Austin, TX.

Case AP, Canfield MA, and the Texas Birth Defects Epidemiology and Surveillance Branch. Developing a State-Specific Cost-of-Illness Estimate for Spina Bifida. Poster presented at the *Annual Meeting of the National Birth Defects Prevention Network,* Nashville, TN, February 2009.

Dieber TB, Hashmi SS, Canfield MA, Nembhard WN, Salemi JL, Hecht JT. Population-based Survival Analysis of Children Born with Orofacial Clefts in Texas. Presented at the Annual American Society of Human Genetics Meeting, November 2-6, 2011, Washington, DC.

Dieber TG, Hashmi SS, Salemi JL, Canfield M, Nembhard WN, Hecht JT. Increased mortality among children born with orofacial clefts. The 60th Annual Meeting of the American Society of

Human Genetics, Washington, DC, November 2-6, 2010.

Leoncini E, Annerén G, Bower C, Cocchi G, Halliday J, Amar E, Bakker MK, Bianca S, Canessa Tapia MA, Castilla EE, Csáky-Szunyogh M, Dastgiri S, Feldkamp M, Gatt M, Hirahara F, Landau D, Lowry RB, Marengo L, Mc Donnell R, Morgan M, Mutchinick OM, Pierini A, Poetzsch S, Ritvanen A, Scarano G, Siffel C, Sípek A, Szabova E, Tagliabue G, Vollset SE, Wertelecki W, Zhuchenko L, Mastroiacovo P. Validity of registration of down syndrome in the International Clearinghouse for Birth Defects Surveillance and Research. Poster session presented at the *12th Annual meeting of the National Birth Defects Prevention Network*, Nashville TN, February 2009.

Lupo PJ, Symanski E, Chan W, Mitchell LE, Waller DK, Canfield MA, Langlois PH. Exposure Misclassification in Studies of Adverse Birth Outcomes: Assessing Effects Due to Residential Mobility. *Annual Meeting of the Society of Pediatric and Perinatal Epidemiologic Research*. Anaheim, CA, June 22-23, 2009.

Marengo LK, Ramadhani T, Canfield MA. Should Aggregate U.S. Census Data Be Used as a Proxy for Individual Household Income in a Birth Defects Registry? Presented at the *36th Annual Meeting of the International Clearinghouse for Birth Defects Surveillance and Research*, Salt Lake City, UT, September 11-15. 2009.

Marengo LK, Ethen MK, Canfield MA. Evaluation of death certificates for finding children with birth defects in Texas. Poster presented at the *Annual Meeting of the National Birth Defects Prevention Network,* Nashville, TN, February 2009.

Marengo LK and Canfield MA. Lessons learned in linking the Texas Birth Defect Registry with newborn screening blood spots for research, 2002 – 2004. Poster presented at the *Annual Meeting of the National Birth Defects Prevention Network,* Nashville, TN, February 2009.

Nembhard WN, Salemi JL, Ethen MK, Fixler DE, and Canfield MA. (2011) Risk of early childhood mortality among children with congenital heart defects by maternal race/ethnicity. Presented as poster at the 3rd *North American Congress of Epidemiology/Annual Meeting of the Society for Epidemiologic Research.* June 22-24, 2011, Montreal, Quebec, Canada.

Nembhard WN, Salemi JL Fixler DE, Ethen MK, and Canfield MA. (2011) Racial/Ethnic disparities in the timing of death during early childhood among children with congenital heart defects. Presented at the *19th World Congress of Epidemiology*, Edinburgh, Scotland, UK, August 7-11, 2011.

Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Canfield MA. Racial/Ethnic Differences in Early Childhood Mortality among Infants Born with Congenital Heart Defects, Texas, 1996-2003. Presented at the *16th Annual Meeting of the MCH Epidemiology Conference*. December 2010, San Antonio, TX.

Nembhard NM, Salemi JL, Ethen M, Fixler DE, Canfield M. Joint Effects of Gestational Age, Fetal Growth and Maternal Ethnicity Affect the Risk of Childhood Mortality for Infants with Birth Defects? Poster presented at the *Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research (SPER)*, June 2010, Seattle, WA.

Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Canfield MA. Racial/Ethnic Differences in Early Childhood Mortality among Infants Born with Congenital Heart Defects, Texas, 1996-2003. *16th Annual Maternal and Child Health Epidemiology Conference*. December 15-17, 2010, San Antonio, Texas.

Nembhard WN, +Salemi JL, Ethen M, and Canfield MA. Separate and Joint Effects of Gestational Age, Size at Birth and Maternal Ethnicity on Childhood Mortality among Infants with Birth Defects. Poster presentation at the *Annual MCH Epidemiology Conference*. December 9-11, 2009, Tampa, Florida.

Nembhard WN, +Salemi JL, Ethen M, and Canfield MA. The role of maternal ethnicity, gestational age and size at birth on childhood survival for infants born with selected birth defects. Oral presentation at the *National Birth Defects Prevention Network Meeting*. February 24, 2009, Nashville, Tennessee.

Nembhard WN, Salemi JL, Ethen M, Canfield M. How Does Gestational Age, Fetal Growth and Maternal Ethnicity Affect the Risk of Childhood Mortality for Infants with Birth Defects? Presented at the *22nd Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research*. June 22-23, 2009, Anaheim, CA.

Nembhard WN, Salemi JL, Ethen MK, Canfield MA. The Role of Gestational Length and Size at Birth on Childhood Survival for Infants Born with Selected Birth Defects. Presented at the *12th Annual Meeting of the National Birth Defects Prevention Network*. February 23-25, 2009, Nashville, TN.

Ramadhani T, Canfield MA, Farag N, Royle M,

Waller DK, Scheuerle A, Correa A, and the National Birth Defects Prevention Study. The Association between Maternal Nativity and Birth Defect Risk Factors, by Race/Ethnicity. Presented by Mark Canfield Ph.D. at the *16th Annual MCH Epidemiology Conference*. December 2010, San Antonio, TX.

Salemi JL, Nembhard WN, Fixler, DA, Canfield MA, and Ethen MA. Mortality among infants with single ventricle heart defects. Poster presentation at the *Annual MCH Epidemiology Conference*. December 9-11, 2009, Tampa, Florida.

Salemi JL, Nembhard WN, Fixler, DA, Canfield MA, and Ethen MA. The joint and separate affects of gestational age, fetal growth and maternal ethnicity on mortality among infants without birth defects. Poster presentation at the *Annual MCH Epidemiology Conference*. December 9-11, 2009, Tampa, Florida.

Salemi JL, Fixler DE, Nembhard WN, Ethen MK, Canfield MA. Survival during the first five years of life among infants with a functional single ventricle, Texas, 1996-2003. Poster presented at the *15th Annual Maternal and Child Health Epidemiology Conference*. Dec 9-11, 2009, Tampa, FL.

Salemi JL, Nembhard WN, Fixler DA, Canfield MA, Ethen MK. Defect-specific survival experience of infants with five major congenital heart defects. Poster presented at the *Annual Meeting of the National Birth Defects Prevention Network,* Nashville, TN, February 2009.

Steck M, Ramadhani T, Carmichael S, Brender J, Case AP, Scheuerle A. The association between periconceptional maternal fish consumption and birth defects. Poster presented at the *American Public Health Association Annual Meeting*. November 9, 2009, Philadelphia, PA.

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