ANNUAL REPORT 2009 with data for 2007

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

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INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

ANNUAL REPORT 2009 (WITH DATA FOR 2007)

Contents

Collaborative Research Projects

Multiple Congenital Anomalies (MCA), 2007

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

Introduction

For the year 2007, we received data from 7 programs, for a total of 2223 reported cases, among 436,343 births (Table 1). Of these, 439 were reported as syndromes and 847 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, 41 of the 47 defect groups (87%) were associated with an O/E ratio greater than 1. Eight of them reached statistical significance at a p<0.001 level, and are shown in Table 2.
A significant excess, at a p< 0.001 level, was found for 10 two-defects (Table 3) and for 6 three-defects combinations (Table 4).
For all comparisons, the data reported from 1992 through 2006, over 6,423,461 births were used as baseline.

Table 1: Cases of MCA, by programme and number of defects (2007).

PROGRAMME	Births	Total cases Reported	Known etiology (syndromes)	< 2 major unrelated defects	2 Or +	Rate
Canada - British Columbia	43,878	134	29	84	21	4.79
France - Central East	57,744	269	37	82	150	25.98
Israel	41,025	34	1	5	28	6.83
Japan	79,588	632	227	250	155	19.48
Mexico	16,418	29	4	0	25	15.23
South America: ECLAMC	140,490	1,009	111	509	389	27.69
Usa: Atlanta	57,200	116	30	7	79	13.81
TOTAL	**436,343**	**2,223**	**439**	**937**	**847**	**19.41**

Table 2: Association rates of defects, among cases with MCA.

Defect group	Observed	Expected	Rate ratio	Excess	Poisson
Congenital heart defects	350	235.2	1.49	114.8	***
Other urinary tract defects	122	81.7	1.49	40.3	***
Other brain defects	85	48.7	1.75	36.3	***
Genitalia defects (ambiguous and other)	70	40.1	1.75	29.9	***
Other gut anomalies	49	20.5	2.40	28.6	***
Deformations (incl clubfoot)	118	90.7	1.30	27.3	***
A/polysplenia	31	7.8	3.97	23.2	***
Broncho-pulmonary defects	44	22.5	1.96	21.5	***
Spina Bifida	46	27.6	1.67	18.4	
Diaphragmatic hernia	45	28.7	1.57	16.3	
Hydrocephaly	70	57.3	1.22	12.7	
Esophageal atresia	66	53.3	1.24	12.7	
Omphalocele	48	35.9	1.34	12.1	
Other small intestinal atresias	20	8.6	2.32	11.4	
Anorectal atresia	94	82.8	1.14	11.2	
Pterygium colli, cystic hygroma	21	10.3	2.05	10.7	
Renal a/dysgenesis	50	39.4	1.27	10.6	
Gastroschisis	21	11.5	1.83	9.5	
An-microphthalmia	32	22.9	1.40	9.1	
Situs inversus	16	8.2	1.96	7.9	
Holoprosencephaly	19	11.2	1.69	7.8	
Cleft palate (incl P Robin)	59	51.4	1.15	7.6	
Encephalocele	22	14.6	1.51	7.4	
Other severe facial defects	22	14.7	1.50	7.3	
Other axial skeleton defects	67	60.0	1.12	7.0	
Cystic kidney	31	24.6	1.26	6.4	
Other eye anomalies	25	18.6	1.34	6.4	
Other ear anomalies	16	10.3	1.55	5.7	
Cleft lip+/palate	80	75.7	1.06	4.3	
Limb reduction defects, other types	24	20.1	1.19	3.9	
Polydactyly	65	61.7	1.05	3.3	
Laryngeo-tracheal defects	6	3.0	2.01	3.0	
Limb reduction defects, transverse	19	16.2	1.17	2.8	
Vessel anomalies	5	2.4	2.10	2.6	
Hypospadias	42	40.2	1.04	1.8	
Other rare defects (Teratoma, sirenomelia)	5	3.8	1.32	1.2	
Duodenal atresia	11	9.9	1.12	1.2	
Anencephaly	12	11.3	1.06	0.7	
An-microtia	38	37.5	1.01	0.5	
Craniostenosis	7	6.6	1.06	0.4	
Sacrum anomalies	3	2.9	1.05	0.2	
Bladder exstrophy/epispadias	5	5.8	0.87	-0.8	
Choanal atresia	6	7.1	0.85	-1.1	
Microcephaly	28	29.6	0.95	-1.6	
Gut malrotation	6	7.8	0.77	-1.8	
Limb reduction defects, preaxial	16	18.8	0.85	-2.8	
Syndactyly	17	23.0	0.74	-6.0	

***= p<0.001

Table 3: Significant two-defect combinations.

Defect-1	Defect-2	N	Exp	Rate Ratio	Excess
Hydrocephaly	Congenital heart defect	28	13.1	2.14	14.9
Broncho-pulmonary defect	Congenital heart defect	22	8.0	2.77	14.1
Other gut anomaly	Congenital heart defect	21	7.7	2.73	13.3
Congenital heart defect	A/polysplenia	18	5.2	3.49	12.8
Other brain defect	Anorectal atresia	13	2.0	6.60	11.0
Situs inversus	A/polysplenia	7	1.0	7.37	6.1
Other gut anomaly	Genitalia defect	7	1.1	6.42	5.9
Other urinary tract defect	A/polysplenia	5	0.4	12.20	4.6
Anencephaly	Genitalia defect	4	0.3	14.81	3.7
Esophageal atresia	A/polysplenia	4	0.3	14.81	3.7

Table 4: Significant Three-defects combinations.

Defect-1	Defect-2	Defect-3	N	Exp	Rate Ratio	Excess
Other brain defects	Congenital heart defects	Other urinary tract defects	9	2.0	4.57	7.0
Other brain defects	Anorectal atresia	Congenital heart defects	6	0.7	8.82	5.3
Congenital heart defects	Situs inversus	A/polysplenia	5	0.5	9.26	4.5
Other gut anomalies	Genitalia defects	Deformations (incl clubfoot)	4	0.1	57.14	3.9
Other brain defects	Anorectal atresia	Other axial skeleton defects	4	0.2	20.00	3.8
Other gut anomalies	Genitalia defects	Other axial skeleton defects	4	0.3	14.81	3.7

Comments:

Significant 2-defects associations:
1. Anencephaly + ambiguous genitalia:
Three of the 4 cases (1 with anophthalmia) also showed a cleft lip with cleft palate, perhaps indicating a dysruptive condition. Despite the description of ambiguous genitalia, in 2 of these cases the code indicating sex specified male, and the suspicion arises as to whether the external genitalia were in fact extremely hypoplastic with undescended testes (secondary to anencephaly), and were therefore described as ambiguous.
The fourth case showed a number of other severe defects (omphalocele, postaxial polydactyly and other postaxial defects, cystic kidneys) and would require further information, such as, for instance, if chromosome anomalies were ruled out. A Meckel syndrome could also be suspected.

The other 4 outstanding 2-defects combinations had laterality defects in common:
1. Esophageal atresia + asplenia: 1 of 4 with an additional transposition of great arteries.
2. Other urinary tract anomalies + a/polysplenia: 3 of the 5 cases showed additional anomalies related to laterality defects (situs inversus, dextrocardia, and biliary duct anomalies).
Two further significant 2-defects, as well as one 3-defects combinations, showed the recognized association of situs inversus, a/polysplenia, and CHD.

Significant associations involving laterality defects were already detected in previous periods (Annual reports 2004, 2005, and 2006).

Among the remaining 2- and 3-defects associations, the involved anomalies were highly unspecific.
Furthermore, and according to the definitions, the following cases potentially exposed to the 3 monitored teratogens (rubella, retinoic acid, and thalidomide) were detected:

Rubella: 1 case
Israel 132007: ASD, microphthalmia, hypoplastic labia minora

Retinoic acid: 1 case
Mexico 133049: Hydrocephaly, cleft palate, VSD, PDA, right microtia, bilat preauricular tags, micrognathia.
This case was already reported in the 1st quarter, 2007.

Thalidomide: 3 cases
Japan 10007: Hydronephrosis, phocomelia, esophageal atresia, tetralogy of Fallot
South America: ECLAMC A3905107: Phocomelia upper limb atypical, sacral spina bifida, other heart defect
South America: ECLAMC G1111907: Hydrocephaly, other heart defect, intercallary upper limb defect

Prenatal Diagnosis and Down Syndrome, 2007

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

Introduction

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

2007 Data

During 2007, 23 programs (Norway, Slovak and Wessex joined the survey for the first time and provided data (Table 1) on 2743 DS cases, 1,142 of them (41.6%) prenatally diagnosed and terminated. The total number of births under surveillance in the 23 programmes was 1,430,697.
The percentage of ToP (Table 2) ranged from the lowest values in USA:Texas (3.4%), USA: Utah (7.8%), Russia:Moscow Region (9.7%), and USA:Atlanta (12.2%), to the highest –as in the previous years- in the registries of French and Italian programs. The French registries show percentages of ToP that ranged from 81% of Paris and 78.9% of REMERA, to 71.2% of Strasbourg, with a mean value of 77.8%. For the 4 Italian registries the percentages of terminations range from the highest of BDRCam (69.6%), Tuscany (65.9%) and IMER (68.4%), to the lowest of North-East (35.7%) with a mean value of 59.9%.
In the European registries that provided a data set of 15 years (1993-2007), a regular increase in the percentage of ToP has been observed, passing from the lowest values of the first three years 41.5% in 1993, 45.9% in 1994, 48.5% in 1995, to the highest values of the years 2003 and 2004 (respectively 68.9% and 69.7%) while in the years 2005 and 2006 we observed a decreasing trend (respectively 65.4% and 55.9%). In 2007 the percentage is similar to the previous years i.e., 67.6% (714/1056).
The comparison of the percentage of ToP in 2007, in all the 15 West European Countries (964/1523) and the extra-European Countries (Canada: Alberta, Cuba, and the three USA registries: Atlanta, Texas and Utah) (113/971) is highly significantly different (62.2% vs 11.6% , $\chi 2 = 280.4$ $p< .0001$).

Terminations are directly related to the maternal age (Table 2): the lower is the maternal age class (≤29 years) the lower the percentage of terminations; and the higher the maternal age classes (38-39 and ≥ 40) the higher the percentages.
The percentage of mothers aged over 35 years (Table3), has increased year by year. In many registries it is over 20% (Northern Netherlands:20.1%; Wessex: 20.8%; Sweden: 21.7% and ItalyBDRCam: 22.3%. France:Paris and two of the Italian programs (IMER and Tuscany) show the highest values: 28.6%, 29.9% and 32.1% respectively .
The greater percentage of terminations are frequently detected in the registries that show the higher percentages of higher aged mothers. In fact overall, the proportion of DS pregnancies which were terminated among women at higher risk (≥35 years old), was over 74% in all the three France registries (Paris:83.1%; REMERA:79.2% and Strasbourg:77.5%); in two of the Italian (IMER: 74.5% and BDRCam: 74.%) where we observe the higher percentage of mothers aged over 35 years old. There is only one exception and this is observed in the Czech registry where in spite of a very high percentage of ToP (85.4%) in mothers aged ≥35 years we observe a very low percentage (10.9%) of aged mother at delivery. Percentages of ToP less than 20% were observed in many registries: Russia: Moscow Region (7.4%); Slovak (9.1%), the three registries of USA: Texas, Atlanta and Utah (5.4%, 17% and 18.5% respectively), and Israel: IBDMS (17.6%) (Table 3).
Also in 2007 the most common technique, used for prenatal diagnosis, was AC (Table 4), with a mean value of 69%. CVS, with a mean value of 29.8%, showed till 2005 a progressive increase year by year: 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. In the last two years the use of CVS, has been quite stable (34.7% in 2006 and 29.8% in 2007).
In the registries Northern-Netherlands, France:Strasbourg and Canada:Alberta, CVS is the most used technique of prenatal detection with a rate of 85.7%, 63% and 53.1% 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 Netherlands (13.5±1.7) and in Canada:Alberta (15.9±2.1wks) (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 Italy:Tuscany (11wks) and the highest in France:Strasbourg (17.3±4.7 wks) (Table 5).

The prevalence at birth of DS decreased in the majority of the 14 programmes that can provide the rates for all the 14 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, all the three French registries (Paris, REMERA, and Strasbourg), all the four Italian registries (BRDCam, Tuscany, IMER and North East) (Table 6). These are the same registries that showed the highest rates of ToP and an increase in the terminations year by year.

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
AUSTRALIA	X	X	X	X	X	X				X	X	X	X	X	
CANADA: ALBERTA					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
CUBA													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
FRANCE:CE/REMERA	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
FRANCE: STRASBOURG	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
GERMANY: SAXONY-ANHALT								X	X	X	X	X	X	X	X
ISRAEL: IBDMS	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
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
RUSSIA: MOSCOW REGION											X	X	X	X	X
NORWAY															X
NORTHERN NETHERLANDS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
SLOVAK												X			X
SWEDEN								X	X	X	X	X	X		X
USA: ATLANTA	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
USA: TEXAS														X	X
USA: UTAH												X	X	X	X
WALES												X	X	X	X
WESSEX															X

Table 2. Percentage (%) of pregnancy terminations (TOP) among the total number of cases recorded in 2007

Monitoring Program	Maternal Age (years)					
	<= 29	30 – 34	35 – 37	38 – 39	>= 40	Total
Canada: Alberta	20.0	22.2	37.9	50.0	35.7	31.6
Czech Republic	64.5	77.3	78.6	96.0	86.1	77.2
Cuba	3.3	23.8	20.7	63.6	60.9	32.0
Finland	38.2	45.0	65.4	55.6	65.1	53.6
France: CE/REMERA	81.8	84.6	69.7	85.7	88.0	78.9
France: Paris	69.2	73.7	84.2	76.5	85.1	81.0
France: Strasbourg	62.5	60.0	100	66.7	75.0	71.2
Germany Saxony-Anhalt	44.4	33.3	42.9	0	100	44.0
Israel: IBDMS	25.0	50.0	20.0	0	20.0	21.7
Italy: BDRCam.	57.1	55.6	81.8	66.7	74.1	69.6
Italy: IMER	40.0	69.2	68.0	81.8	78.9	68.4
Italy: North-East	28.6	31.3	53.8	37.5	43.3	35.7
Italy: Tuscany	50.0	50.0	66.7	70.0	75.0	65.9
Russia: Moscow Region	6.9	21.4	6.7		7.7	9.7
Norway	23.5	25.9	38.1	57.1	38.8	
Northern Netherlands	25.0	18.2	33.3	100	0	25.9
Slovak	15.4	23.1	16.7		0	16.2
Sweden	19.1	42.9	61.1	79.4	80.3	54.9
USA: Atlanta	3.7	16.7	16.7	21.4	11.8	12.2
USA: Texas	1.4	2.8	1.3	7.2	7.7	3.4
USA: Utah	2.7	0	20.0	16.7	18.8	7.8
Wales	41.2	50.0	83.3	71.4	42.1	55.0
Wessex	5.6	53.8	68.8	72.7	45.5	51.1

Table 3. Percentage of mothers aged 35 and over in the participating programs 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
Canada: Alberta	15.5	40.0	51.5	85.9
Czech Republic	10.9	85.4	12.1	83.2
Cuba	-	45.9	-	-
Finland	18.6	61.9	34.6	95.7
France: CE/REMERA	18.6	79.2	14.0	67.1
France: Paris	28.6	83.1	8.0	47.5
France: Strasbourg	17.3	77.5	23.4	103.9
Germany: Saxony-Anhalt	13.4	50.0	21.3	42.6
Israel: IBDMS	19.8	17.6	17.3	20.9
Italy: BDRCam.	22.3	74.0	10.4	40.0
Italy: IMER	29.9	74.5	11.5	45.3
Italy: North-East	-	50.0	-	-
Italy: Tuscany	32.1	70.6	10.1	34.2
Russia: Moscow Region	8.2	7.4	51.6	55.7
Norway	19.3	46.8	35.6	66.8
Northern Netherlands	20.1	33.3	22.5	33.7
Slovak	9.6	9.1	19.1	21.0
Sweden	21.7	73.2	18.2	67.6
USA: Atlanta	17.0	17.0	39.0	48.3
USA: Texas	11.4	5.4	49.3	52.1
USA: Utah	9.3	18.5	42.7	52.4
Wales	17.1	62.2	28.7	75.9
Wessex	20.8	59.2	15.9	32.4

Table 4 . Down Syndrome techniques of prenatal diagnosis (number of cases) registered in 2007 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
Canada: Alberta	2	6	-	3	11	5	-	-	4	4	-	2	17	15	-	5
Czech Republic	19	89	-	-	12	45	-	-	3	27	1	-	34	161	1	-
Cuba	1	4	1	-	4	16	-	-	2	11	1	-	7	31	2	-
Finland	18	13	-	-	17	20	-	-	10	18	-	-	45	51	-	-
France : CE/REMERA	11	36	-	4	9	26	-	-	7	15	-	-	27	77	-	4
France: Paris	7	16	-	-	10	19	-	-	14	26	-	-	32	61	-	-
France: Strasbourg	10	5	1	-	13	6	-	-	6	6	-	-	29	17	1	-
Germany: Saxony-Anhalt	-	6	-	-	-	3	-	-	-	2	-	-	-	11	-	-
Israel: IBDMS	-	2	-	-	-	1	-	-	-	2	-	-	-	5	-	-
Italy: BDRCam.	-	9	-	-	-	17	-	-	-	20	-	-	-	46	-	-
Italy: IMER	8	5	-	-	11	15	-	-	5	10	-	-	24	30	-	-
Italy: North-East	4	2	-	1	5	4	-	1	1	4	-	3	10	10	-	5
Italy: Tuscany	1	3	-	-	3	11	-	1	4	4	-	1	8	18	-	2
Russia: Moscow Region	-	-	5	-	-	-	1	-	-	-	1	-	-	-	7	-
Northern Netherlands	2	-	-	-	4	1	-	-	-	-	-	-	6	1	-	-
Sweden	1	12	-	23	2	26	-	32	2	12	-	35	5	51	-	90
USA: Atlanta	1	2	-	-	1	5	-	-	-	2	-	-	2	9	-	-
USA: Utah	-	1	-	-	-	2	-	-	3	-	-	-	3	3	-	-
Wales	5	10	-	-	4	16	-	-	2	5	-	-	11	31	-	-
Wessex	12	7	-	-	7	12	-	-	4	6	-	-	23	25	-	-
Total	**102**	**228**	**7**	**31**	**113**	**250**	**1**	**34**	**67**	**174**	**3**	**41**	**282**	**652**	**11**	**106**

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

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
Canada: Alberta	14.00±0.00	17.83±0.98	17.00±2.00	14.53±1.13	18.33±0.71	15.96±2.12
Czech Republic	13.63±1.07	18.95±2.67	18.01±3.20	13.53±1.06	19.04±2.02	18.09±2.81
Finland	14.56±0.86	17.92±1.32	15.97±1.99	14.26±1.70	17.76±1.13	16.31±2.22
France: CE/REMERA	13.73±0.90	19.89±3.75	18.45±4.22	14.00±1.03	19.78±3.24	18.16±3.83
France: Paris	14.00±1.53	21.63±4.49	19.30±5.22	13.92±0.93	20.02±3.26	17.88±3.98
France: Strasbourg	17.30±4.72	22.00±0.71	18.87±4.44	17.68±4.45	20.50±3.12	18.77±4.17
Germany: Saxony- Anhalt	-	21.83±1.34	21.83±1.34	-	18.80±1.10	18.80±1.10
Israel: IBDMS	-	25.00±0.00	25.00±0.00	-	26.00±0.00	26.00±0.00
Italy: BDRCam.	-	19.78±3.23	19.78±3.23	-	20.11±2.89	20.11±2.89
Italy: IMER	15.57±2.57	20.20±0.84	17.50±3.09	15.13±2.42	20.12±1.33	18.17±3.06
Italy: North-East	14.50±1.291	20.00±1.41	16.33±3.08	15.17±1.17	19.38±1.77	17.57±2.62
Italy: Tuscany	11.00±0.00	18.67±2.08	16.75±4.19	11.86±0.69	17.29±1.64	15.48±2.96
Northern Netherlands	14.50±2.12	22.00±0.00	17.00±4.58	13.50±1.73	-	13.50±1.73
USA: Atlanta	15.00±0.00	21.50±4.95	19.33±5.13	14.00±0.00	19.33±2.16	18.57±2.82
USA: Utah	-	19.00±0.00	19.00±0.00	19.33±0.58	17.00±0.00	14.80±2.05
Wales	13.80±1.30	19.56±2.60	17.50±3.59	13.83±2.93	17.95±2.24	17.00±2.94
Wessex	13.25±0.62	18.57±2.07	15.21±2.94	13.82±0.87	17.22±0.81	15.93±1.87

Table 6. Prevalence at birth (x 10,000) of DS by year in the participanting programs.

Programme	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007
Australia										9,98	8,49	11,03	10,85	11,45	
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
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
Cuba													8.31	8,72	
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
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
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
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 Anhalt	5,79	6,33	7,43	7,86	8,33	13,65	6,09	6,38	8,26	9,08	5,30	9,18	2.90	10,0	8,01
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
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
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
Russia: Moscow region												10,66	13.64	12,11	10,97
Norway															12,41
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
Slovak															5,67
Sweden							14,01	11,01	14,59	13,31	15.,47	10,56	12.69		11,89
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
USA: Texas														11,96	13,50
USA: Utah												14,01	13.19	11,91	12,83
Wales												11,69	13,12	10,05	10,40
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 2009 Award

The Award of the 2009 "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 **Somer Dawson** as Author of the high quality, original peer-reviewed article "Birth Defects in children with autism spectrum disorders: a population-based, nested case-control study", published in the American Journal of Epidemiology.

Birth defects in children with autism spectrum disorders: a population-based, nested case-control study.
Dawson S, Glasson EJ, Dixon G, Bower C.
Am J Epidemiol. 2009 Jun 1;169(11):1296-303. Epub 2009 Apr 16.
Telethon Institute for Child Health Research, Centre for Child Health Research, The University of Western Australia, West Perth, Western Australia, Australia.

Abstract
The causes of autism spectrum disorders (ASDs) are unknown, although genetic and environmental influences have been implicated. Previous studies have suggested an association with birth defects, but most investigators have not addressed associations with specific diagnostic categories of ASD. In this study, the authors investigated the associations between birth defects and autism, Asperger syndrome, and pervasive developmental disorder not otherwise specified. Using Western Australian population-based linked data, the authors compared all children with ASD born in Western Australia during 1980-1995 (n = 465) with their siblings (n = 481) and population controls (n = 1,313) in a nested case-control study. The prevalence of birth defects was significantly higher in ASD cases than in population controls; this difference remained significant after adjustment for confounding factors. Odds ratios for birth defects were similar for autism (odds ratio (OR) = 2.0, 95% confidence interval (CI): 1.3, 3.0) and pervasive developmental disorder not otherwise specified (OR = 2.2, 95% CI: 1.1, 4.3) but not for Asperger syndrome (OR = 0.5, 95% CI: 0.1, 1.9). Birth defects in case siblings were not significantly different from those in cases and population controls. The association between birth defects and ASD may be due to underlying genetic and/or environmental factors common to both ASD and birth defects, or birth defects may predispose a child to ASD.

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
Australia: National	Population-based National	1981	1 year	20 weeks or 400 grams	Permitted, Reported
Australia:VBDR	Population-based Statewide	2002	Up to 18 years	20 weeks or 400 grams	Permitted, Reported
Australia: WABDR	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
China: BDSS.Beijing	Population-based, Four Provinces	1997	6 weeks	20 weeks	Permitted, Not reported
China: CBDMN	Hospital-based	1985	7 days	28 weeks	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
England and Wales	Population-based National	1974	1995 onwards no limit	24 weeks	Permitted, Reported only for a few selected malformations
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
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: ISMAC	Hospital-based Regional	1991	1 year	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

Synopsis of Contributing Monitoring Systems

Monitoring Program	Coverage	Year Joined ICBDSR	Maximum age at diagnosis	Criteria defining stillbirths	Termination of Pregnancy (ToP)
Italy-Tuscany:RTDC	Population-based Regional	1998	1 year	180 days (25 weeks + 5 days)	Permitted, Reported
Italy: Lombardy-RMCL	Population-based Regional	2007		180 days (25 weeks + 5 days)	Permitted, Reported
Japan: JAOG	Hospital-based , National	1988	7 days	22 weeks	Permitted, Not reported
Malta: MCAR	Population-based National	2000	1 year	20 weeks	Not permitted, Not reported
Mexico: RYVEMCE	Hospital based, National	1980	72 hours	20 weeks or 500 grams	Not permitted
New Zealand	Population-based National	1979	No limit	20 weeks or 400 grams	Permitted, Not 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	Non-viable fetuses, 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	28 days	>= 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	Before 2001: 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

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. Includes: 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: National																										
Australia: VBDR									11	14						25					35					
Australia: WABDR									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
China: Beijing																					35					
China: CBDMN	1	2		6	2	7	9		12				18			25		27	28	31	35	37		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					
England and Wales																										
Finland		2			2		8		11,12									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: ISMAC																25										
Italy: North East			5		2					13	15	17	18,20	22					29		35					2
Italy: Tuscany							8																			
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 Africa: SABDSS	1	2			2				11,12							25		27		31	35	37		2	2	2
South America: ECLAMC																25										
Spain: ECEMC		3			2													27				37				2
Sweden		2			2				11							25			28	32						2
Ukraine		2,3		6	2	7	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

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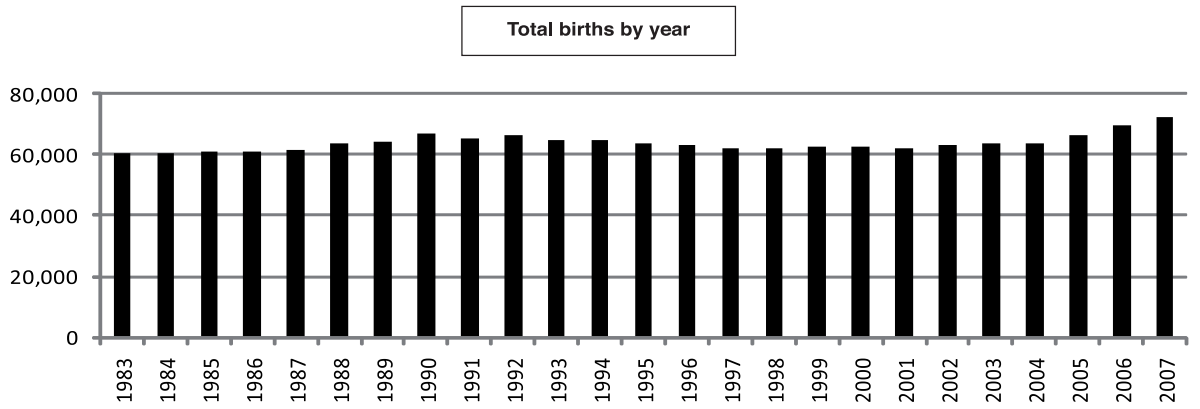
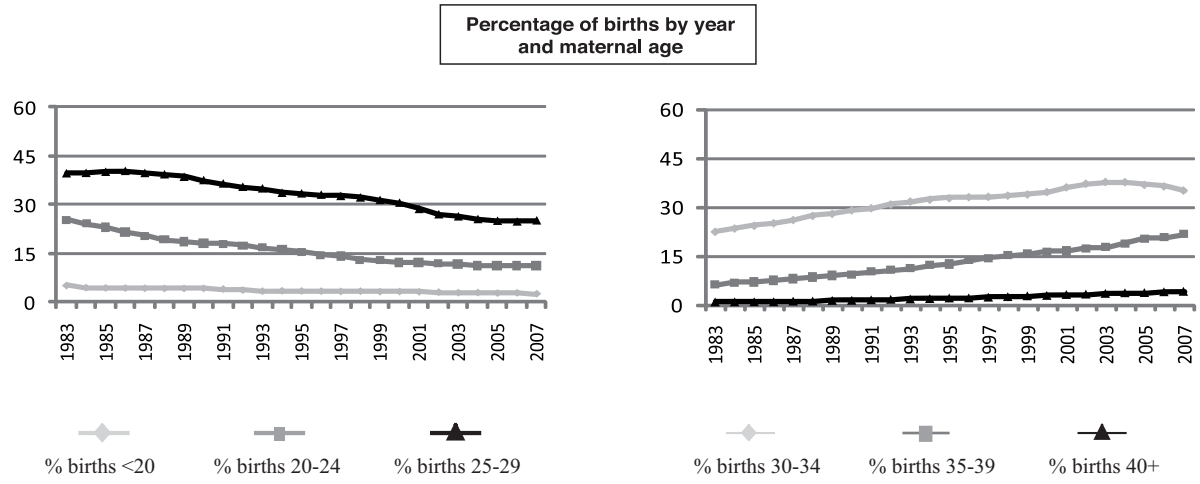
Victorian Birth Defects Register
Victorian Perinatal Data Collection Unit
GPO Box 4003
Melbourne 3001, Australia

Phone: 03-9096 2702

Australia: VBDR





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	86	76.8	Cystic kidney	11	8.6
Spina bifida	34	28.8	Limb reduction defects	8	6.7
Encephalocele	9	28.1	Diaphragmatic hernia	4	6.2
Holoprosencephaly	18	48.6	Omphalocele	37	52.9
Hydrocephaly	22	12.4	Gastroschisis	8	17.8
Hypoplastic left heart syndrome	7	7.4	Trisomy 13	49	62.0
Cleft palate without cleft lip	1	0.6	Trisomy 18	140	71.1
Cleft lip with or without cleft palate	14	6.5	Down syndrome	409	63.5
Renal agenesis	5	14.3			

Total ToPs with births defects = 1,057 (Ratio ToPs/Births: 5.06 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: VBDR, 2007

Live births (LB)	71,780
Stillbirths (SB)	531
Total births	72,311
Number of terminations of pregnancy (ToP) for birth defects	364

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	4	7	27	5.26
Spina bifida	15	12	8	4.84
Encephalocele	3	8	3	1.94
Microcephaly	18	2	0	2.77
Holoprosencephaly	2	2	6	1.38
Hydrocephaly	41	19	8	9.40
Anophthalmos	0	0	0	0.00
Microphthalmos	9	0	0	1.24
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	5	0	0	0.69
Microtia	6	0	1	0.97
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	37	2	1	5.53
Tetralogy of Fallot	21	1	0	3.04
Hypoplastic left heart syndrome	25	6	1	4.43
Coarctation of aorta	35	3	0	5.26
Choanal atresia, bilateral	13	0	0	1.80
Cleft palate without cleft lip	37	2	0	5.39
Cleft lip with or without cleft palate	70	10	6	11.89
Oesophageal atresia/stenosis with or without fistula	19	2	0	2.90
Small intestine atresia/stenosis	7	0	0	0.97
Anorectal atresia/stenosis	20	5	1	3.60
Undescended testis (36 weeks of gestation or later)	359	0	0	49.65
Hypospadias	294	1	0	40.80
Epispadias	5	0	0	0.69
Indeterminate sex	7	2	1	1.38
Renal agenesis	3	8	0	1.52
Cystic kidney	32	7	6	6.22
Bladder exstrophy	2	0	0	0.28
Polydactyly, preaxial	90	3	4	13.41
Total Limb reduction defects (include unspecified)	40	9	3	7.19
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	22	4	27	7.33
Omphalocele	8	6	15	4.01
Gastroschisis	9	4	1	1.94
Unspecified Omphalocele/Gastroschisis	1	0	3	0.55
Prune belly sequence	0	0	1	0.14
Trisomy 13	4	6	15	3.46
Trisomy 18	6	21	46	10.10
Down syndrome, all ages (include age unknown)	69	13	152	32.36
<20	0	1	0	5.44
20-24	3	2	1	7.36
25-29	13	2	6	11.49
30-34	15	2	22	15.37
35-39	28	4	59	57.90
40-44	9	4	33	163.99
45+	1	1	5	451.61
unknown	0	0	26	---

nr = not reported
Includes TOPS at 20 weeks or more for birth defects, but excludes TOPs for psychosocial reasons

Australia: VBDR, Previous years rates 1983 - 2007

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

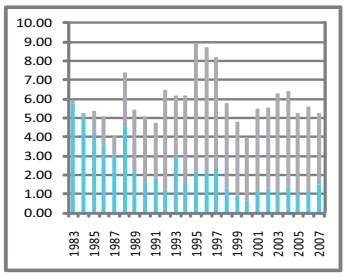
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births			**305,336**	**326,340**	**318,644**	**312,614**	**336,066**
Anencephaly			5.14	5.82	7.63	5.12	5.74
Spina bifida			8.84	8.09	9.04	6.69	6.04
Encephalocele			1.60	1.72	1.88	1.38	1.49
Microcephaly			3.80	2.73	3.04	3.29	2.62
Holoprosencephaly			0.88	1.07	1.44	1.89	1.67
Hydrocephaly			4.49	6.44	8.57	9.76	9.08
Anophthalmos			0.29	0.28	0.09	0.26	0.30
Microphthalmos			1.18	0.92	0.82	0.67	0.60
Unspecified Anophthalmos / Microphthalmos			0.00	0.00	0.00	0.00	0.00
Anotia			0.85	0.52	1.26	0.83	0.74
Microtia			0.23	0.46	0.38	0.48	0.68
Unspecified Anotia / Microtia			0.00	0.00	0.00	0.00	0.00
Transposition of great vessels			4.22	4.99	5.81	5.57	5.80
Tetralogy of Fallot			2.91	3.59	4.05	4.32	3.84
Hypoplastic left heart syndrome			2.91	2.67	2.54	3.45	4.26
Coarctation of aorta			6.65	5.73	4.33	4.13	4.70
Choanal atresia, bilateral			1.74	1.90	2.07	2.02	1.73
Cleft palate without cleft lip			7.93	6.80	7.97	8.92	8.72
Cleft lip with or without cleft palate			10.74	9.90	9.89	11.16	10.44
Oesophageal atresia / stenosis with or without fistula			3.77	3.34	4.17	2.81	3.24
Small intestine atresia / stenosis			1.02	1.07	1.16	1.76	1.79
Anorectal atresia / stenosis			3.67	3.77	4.99	4.09	3.93
Undescended testis (36 weeks of gestation or later)			10.48	37.60	46.89	48.30	50.76
Hypospadias			17.42	28.90	33.36	35.99	37.22
Epispadias			0.29	0.31	0.47	0.64	0.68
Indeterminate sex			1.38	3.09	2.42	1.50	1.58
Renal agenesis			3.44	2.73	2.48	2.75	1.67
Cystic kidney			3.05	4.26	5.90	6.62	5.83
Bladder exstrophy			0.49	0.18	0.44	0.51	0.33
Polydactyly, preaxial			7.70	8.95	10.42	10.52	12.20
‘Total Limb reduction defects (include unspecified)			5.70	6.28	7.31	5.95	5.86
Transverse			nr	nr	nr	nr	nr
Preaxial			nr	nr	nr	nr	nr
Postaxial			nr	nr	nr	nr	nr
Intercalary			nr	nr	nr	nr	nr
Mixed			nr	nr	nr	nr	nr
Unspecified			nr	nr	nr	nr	nr
Diaphragmatic hernia			3.14	3.52	3.83	3.42	3.27
Omphalocele			2.65	3.49	3.30	3.68	3.18
Gastroschisis			0.82	1.62	2.23	2.66	2.02
Unspecified Omphalocele / Gastroschisis			0.56	0.58	0.91	0.54	0.30
Prune belly sequence			0.33	0.31	0.41	0.13	0.12
Trisomy 13			1.11	1.38	2.48	2.85	3.48
Trisomy 18			2.36	3.86	5.55	6.72	9.58
Down syndrome, all ages (include age unknown)			13.56	16.52	19.90	26.61	30.02
<20			8.52	8.12	10.11	3.97	6.41
20-24			7.13	8.70	9.30	8.16	8.37
25-29			9.18	8.25	9.05	10.85	8.40
30-34			14.63	16.14	14.82	18.62	16.79
35-39			39.22	48.14	48.48	57.00	57.02
40-44			113.35	113.18	161.85	191.78	163.28
45+			66.23	186.34	460.83	306.75	319.15
unknown			---	---	---	---	---

nr = not reported

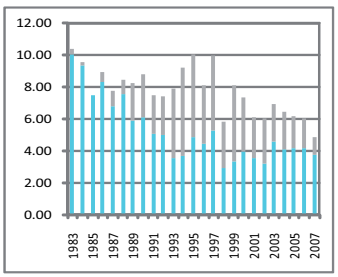
Australia: VBDR

'Time trends 1983-2007 (Birth prevalence rates per 10,000)

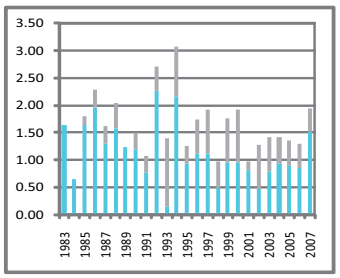
Anencephaly



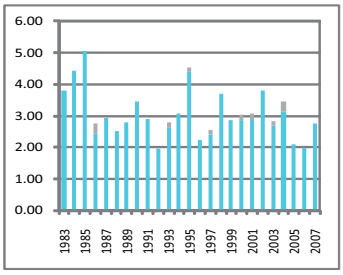
Spina Bifida



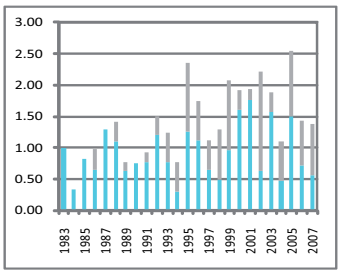
Encephalocele



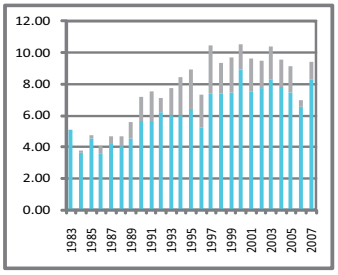
Microcephaly



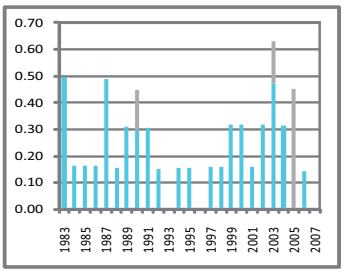
Holoprosencephaly



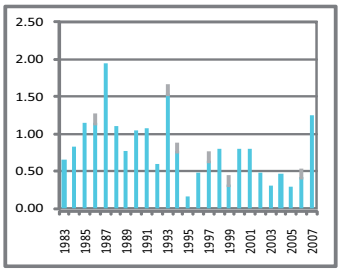
Hydrocephaly



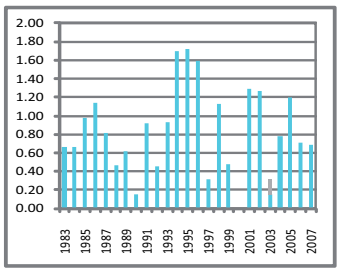
Anophthalmos



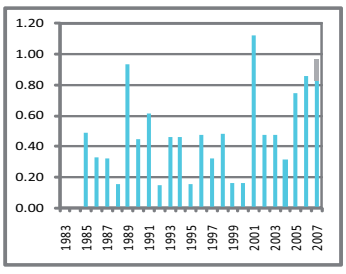
Microphthalmos



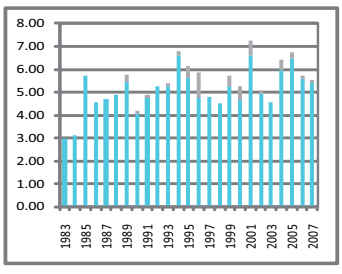
Anotia



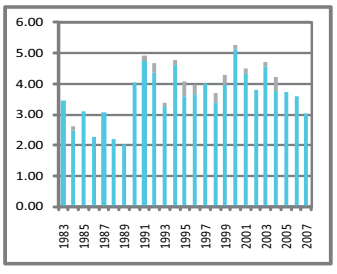
Microtia



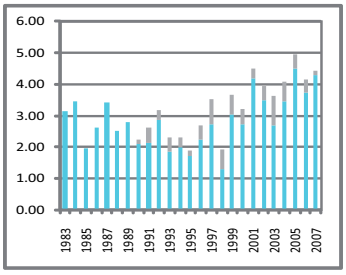
Transposition of great vessels



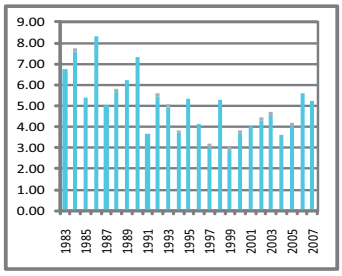
Tetralogy of Fallot



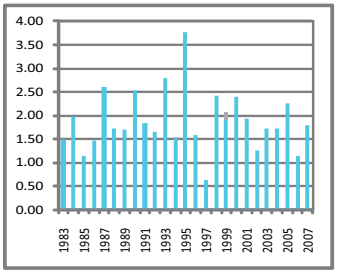
Hypoplastic left heart syndrome



Coarctation of aorta



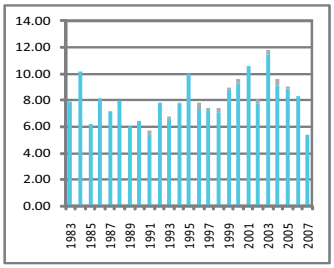
Choanal atresia, bilateral



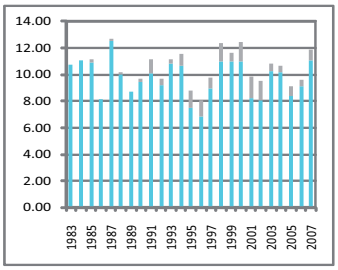
Note: L+S rates, ToP rates

Australia: VBDR

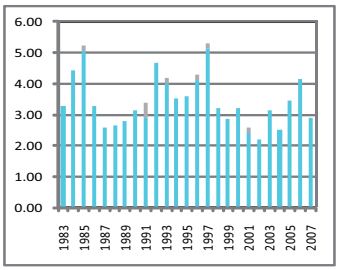
Cleft palate without cleft lip



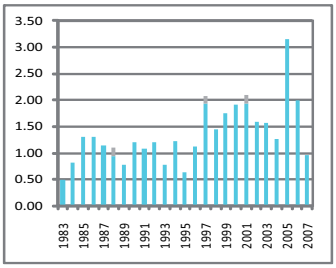
Cleft lip with or without cleft palate



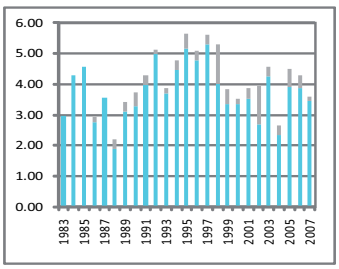
Oesophageal atresia/stenosis with or without fistula



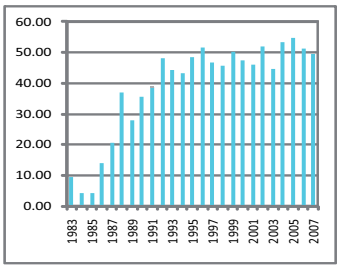
Small intestine atresia/stenosis



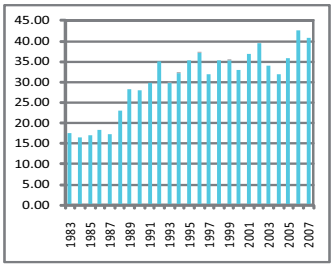
Anorectal atresia/stenosis



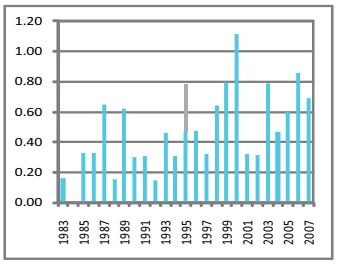
Undescended testis



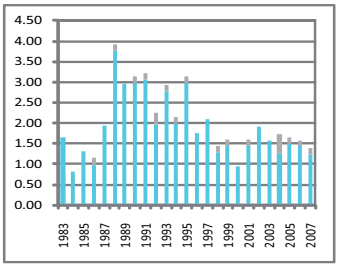
Hypospadias



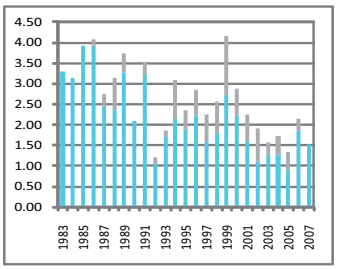
Epispadias



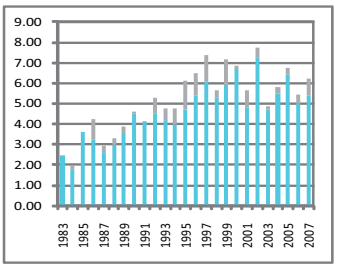
Indeterminate sex



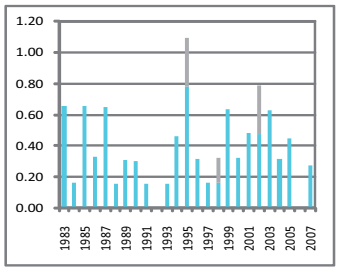
Renal agenesis



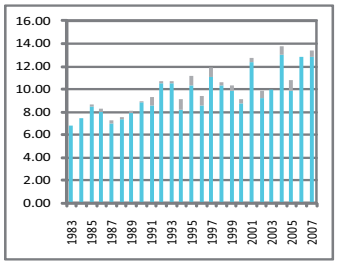
Cystic kidney



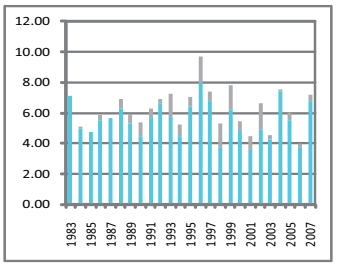
Bladder exstrophy



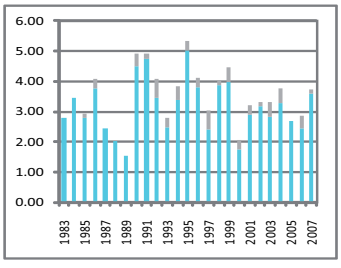
Polydactyly, preaxial



Limb reduction defects



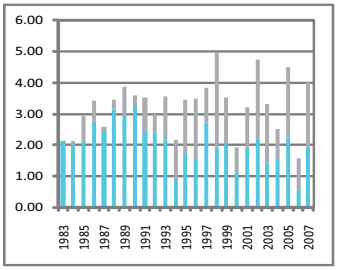
Diaphragmatic hernia



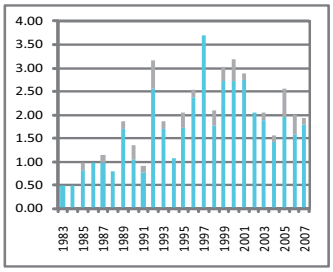
Note: L+S rates, ToP rates

Australia: VBDR

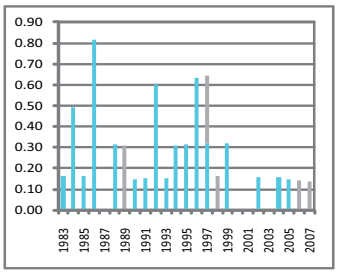
Omphalocele



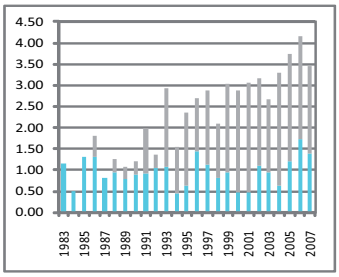
Gastroschisis



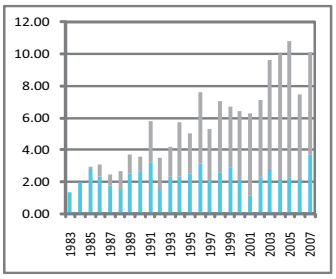
Prune belly sequence



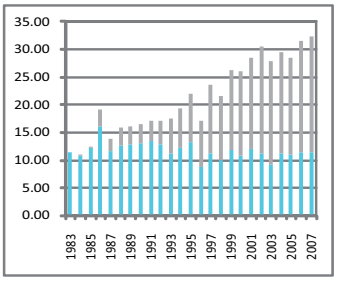
Trisomy 13



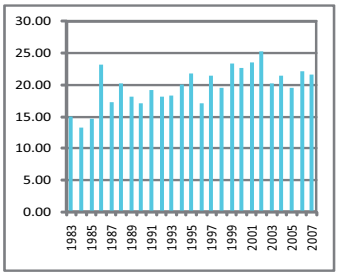
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Australia: WABDR
Western Australian Birth Defects Registry

History:
The Registry was established in 1980, and is currently located in a teaching obstetric hospital. The objectives of the Registry have always been to establish how often birth defects occur, to conduct research into causes and prevention of birth defects, to provide health professionals and the public with information about birth defects, 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. Birth defects diagnosed prenatally and up to the age of 6 years, in stillbirths, terminations of pregnancy and livebirths are included.

Legislation and funding:
Following a period of short term funding from both Federal and State sources, the Registry is now wholly funded by the Western Australian Department of Health. There are several statutory sources of information (birth, death and hospital data collections), and a large number of voluntary sources. Statutory notification is being considered by the Department of Health.

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).

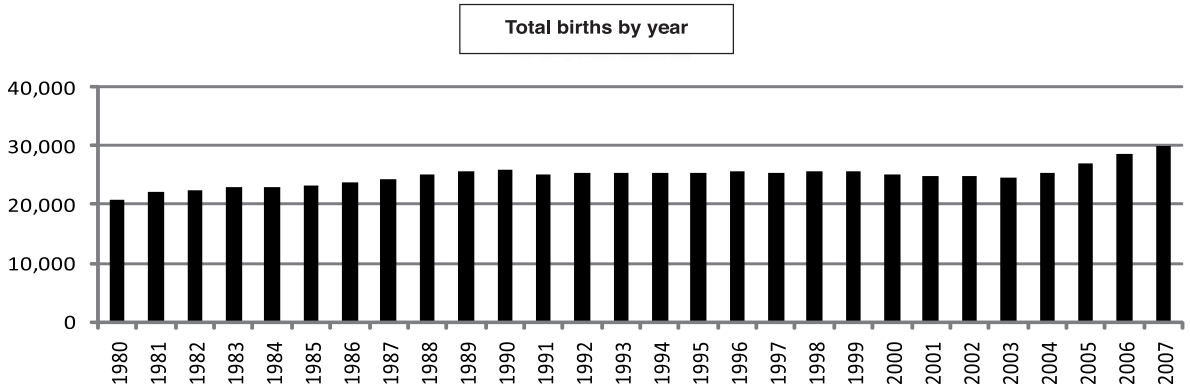
Voluntary sources: Maternity and paediatric hospitals, Obstetricians, paediatricians, orthopaedic surgeons, Community and Child Health Nurses, Cytogenetic laboratories, Pathology services (including prenatal screening services), Ultrasound practices Genetic Services, Disability services.

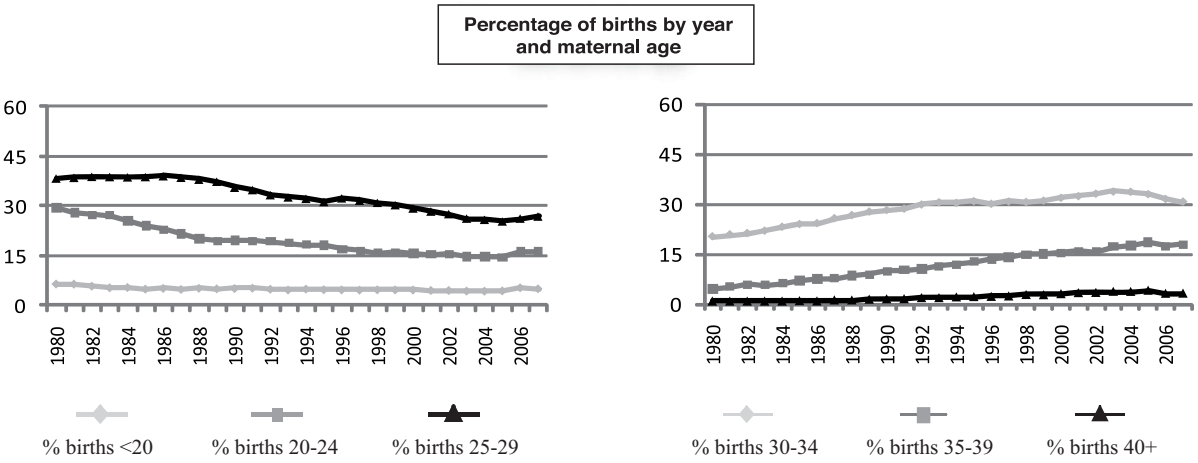
Exposure information:
No exposure information is routinely collected

Background information:
The data on the Registry 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.

Addresses and Staff:
Clinical Professor Carol Bower, Programme Director
Western Australia Birth Defects Registry (WABDR)
King Edward Memorial Hospital
PO Box 134 Subiaco 6904, Western Australia
Phone: 618 9340 2721
Fax: 618 9340 2636
E-mail: caroline.bower@health.wa.gov.au
Website: http://www.kemh.health.wa.gov.au/services/birth_defects/index.htm

Australia: WABDR





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	41	89.1	Cystic kidney	9	15.0
Spina bifida	41	71.9	Limb reduction defects	23	38.3
Encephalocele	7	53.8	Diaphragmatic hernia	5	18.5
Holoprosencephaly	12	75.0	Omphalocele	23	76.7
Hydrocephaly	44	59.5	Gastroschisis	4	11.1
Hypoplastic left heart syndrome	10	62.5	Trisomy 13	22	88.0
Cleft palate without cleft lip	11	15.1	Trisomy 18	58	81.7
Cleft lip with or without cleft palate	22	22.7	Down syndrome	151	64.0
Renal agenesis	10	26.3			

Total ToPs with births defects = 578 (Ratio ToPs/Births: 6.74 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Australia: WABDR, 2007

Live births (LB)	29,888
Stillbirths (SB)	189
Total births	30,077
Number of terminations of pregnancy (ToP) for birth defects	190

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	16	5.98
Spina bifida	4	0	10	4.65
Encephalocele	2	0	3	1.66
Microcephaly	6	0	2	2.66
Holoprosencephaly	1	0	4	1.66
Hydrocephaly	9	1	14	7.98
Anophthalmos	1	0	1	0.66
Microphthalmos	4	0	2	1.99
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.66
Microtia	1	0	0	0.33
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	10	0	4	4.65
Tetralogy of Fallot	3	1	2	1.99
Hypoplastic left heart syndrome	1	0	4	1.66
Coarctation of aorta	10	0	1	3.66
Choanal atresia, bilateral	1	0	0	0.33
Cleft palate without cleft lip	17	0	4	6.98
Cleft lip with or without cleft palate	26	1	11	12.63
Oesophageal atresia/stenosis with or without fistula	12	1	1	4.65
Small intestine atresia/stenosis	7	1	1	2.99
Anorectal atresia/stenosis	6	0	6	3.99
Undescended testis (36 weeks of gestation or later)	70	0	0	23.27
Hypospadias	97	0	0	32.25
Epispadias	1	0	0	0.33
Indeterminate sex	0	0	0	0.00
Renal agenesis	9	0	3	3.99
Cystic kidney	14	0	3	5.65
Bladder exstrophy	1	0	0	0.33
Polydactyly, preaxial	15	0	3	5.98
Total Limb reduction defects (include unspecified)	9	0	4	4.32
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	4	0	2	1.99
Omphalocele	0	1	6	2.33
Gastroschisis	11	0	0	3.66
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	7	2.33
Trisomy 18	2	0	17	6.32
Down syndrome, all ages (include age unknown)	29	3	51	27.60
<20	0	0	0	0.00
20-24	2	0	1	6.15
25-29	5	0	4	11.15
30-34	6	1	12	20.54
35-39	10	2	17	53.86
40-44	5	0	16	222.93
45+	1	0	1	689.66
unknown	1	0	0	---

nr = not reported

Australia: WABDR, Previous years rates 1980 - 2007

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

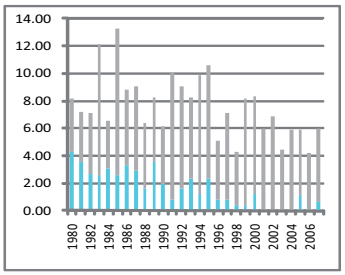
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births		**65,427**	**117,486**	**127,052**	**127,051**	**126,395**	**135,943**
Anencephaly		7.49	9.96	7.95	8.19	6.72	5.30
Spina bifida		8.41	9.02	9.05	7.56	6.96	6.99
Encephalocele		1.99	1.45	2.13	1.57	1.27	1.40
Microcephaly		5.81	5.45	4.88	5.82	6.09	4.63
Holoprosencephaly		0.92	1.70	1.89	2.20	1.98	1.91
Hydrocephaly		7.18	6.72	6.85	10.70	8.15	7.65
Anophthalmos		0.76	0.51	0.31	0.39	0.87	0.37
Microphthalmos		1.38	1.96	1.89	1.89	2.29	1.25
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		1.68	1.79	1.65	2.28	2.53	1.40
Microtia		0.92	0.60	0.87	1.34	1.82	0.88
Unspecified Anotia / Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		2.75	4.51	4.64	4.64	4.51	5.15
Tetralogy of Fallot		2.45	3.23	4.33	3.38	3.32	2.80
Hypoplastic left heart syndrome		1.83	1.53	2.36	2.36	1.50	1.69
Coarctation of aorta		5.66	5.28	5.04	5.51	5.70	5.74
Choanal atresia, bilateral		1.07	1.53	1.02	0.71	1.03	0.15
Cleft palate without cleft lip		8.25	8.51	9.92	11.18	12.26	8.97
Cleft lip with or without cleft palate		10.85	14.04	10.07	12.91	12.18	12.73
Oesophageal atresia / stenosis with or without fistula		3.21	3.49	2.60	3.38	3.40	4.49
Small intestine atresia / stenosis		2.90	2.64	2.83	2.83	2.61	2.87
Anorectal atresia / stenosis		5.81	4.26	6.85	6.53	6.41	5.96
Undescended testis (36 weeks of gestation or later)		64.04	65.54	71.47	59.19	53.48	34.28
Hypospadias		23.54	31.32	29.75	36.52	38.61	32.66
Epispadias		0.31	0.17	0.47	0.24	0.16	0.22
Indeterminate sex		0.00	0.34	0.31	0.39	0.24	0.07
Renal agenesis		3.06	3.83	4.01	4.41	4.67	5.00
Cystic kidney		3.36	3.06	5.67	8.34	8.47	7.80
Bladder exstrophy		0.00	0.17	0.39	0.39	0.24	0.22
Polydactyly, preaxial		9.48	10.98	9.76	12.59	10.68	11.25
'Total Limb reduction defects (include unspecified)		4.89	4.68	6.14	7.32	10.44	6.99
Transverse		nr	nr	nr	nr	nr	nr
Preaxial		nr	nr	nr	nr	nr	nr
Postaxial		nr	nr	nr	nr	nr	nr
Intercalary		nr	nr	nr	nr	nr	nr
Mixed		nr	nr	nr	nr	nr	nr
Unspecified		nr	nr	nr	nr	nr	nr
Diaphragmatic hernia		3.67	2.89	2.91	3.54	3.56	3.16
Omphalocele		1.83	2.81	3.15	3.31	3.48	4.49
Gastroschisis		1.53	1.62	2.05	3.54	3.40	3.83
Unspecified Omphalocele / Gastroschisis		0.00	0.00	0.00	0.00	0.00	0.00
Prune belly sequence		0.31	0.85	0.39	0.55	0.08	0.00
Trisomy 13		0.92	0.94	1.10	1.50	2.53	3.31
Trisomy 18		1.68	1.62	2.99	4.64	6.72	7.65
Down syndrome, all ages (include age unknown)		11.16	14.13	15.98	19.52	23.26	27.07
<20		2.46	9.90	4.61	8.24	13.54	7.72
20-24		5.96	4.56	8.84	5.31	6.55	8.14
25-29		9.47	7.87	8.76	8.59	12.40	9.02
30-34		12.56	15.76	14.24	18.31	19.40	19.25
35-39		38.02	48.49	41.07	46.61	42.24	57.70
40-44		71.68	228.07	171.52	172.93	155.50	171.49
45+		833.33	317.46	588.24	338.98	486.49	502.51
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

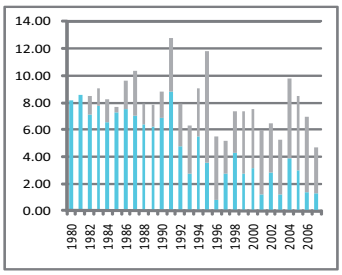
Australia: WABDR

'Time trends 1980-2007 (Birth prevalence rates per 10,000)

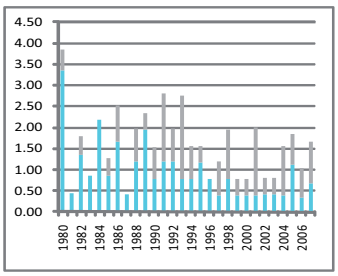
Anencephaly



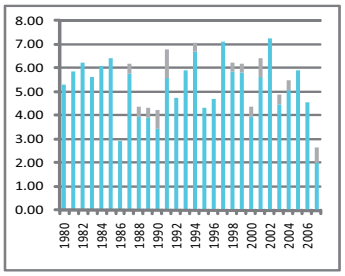
Spina Bifida



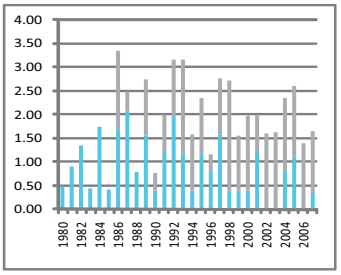
Encephalocele



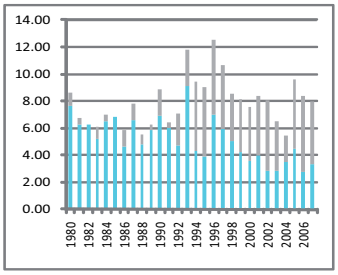
Microcephaly



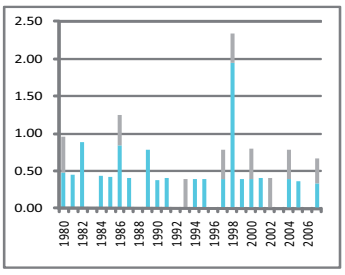
Holoprosencephaly



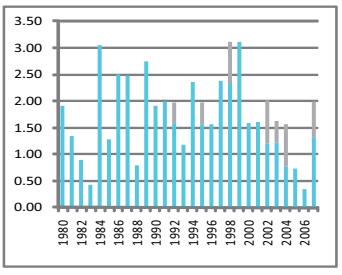
Hydrocephaly



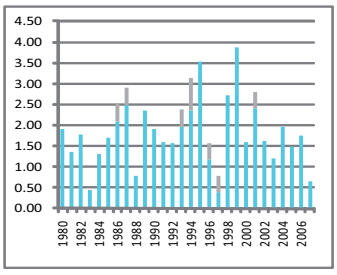
Anophthalmos



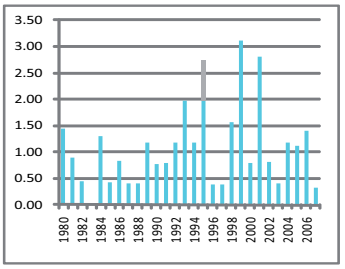
Microphthalmos



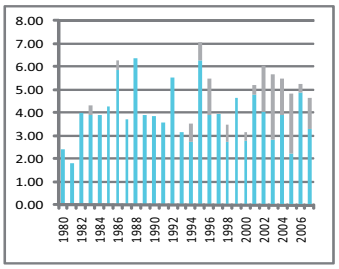
Anotia



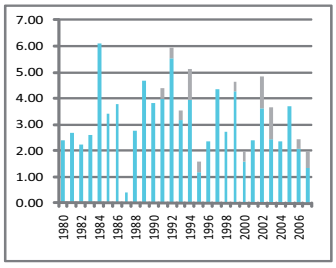
Microtia



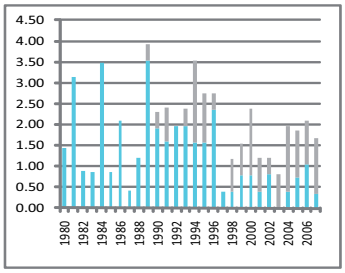
Transposition of great vessels



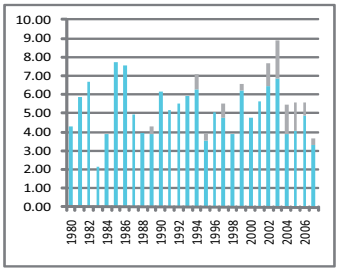
Tetralogy of Fallot



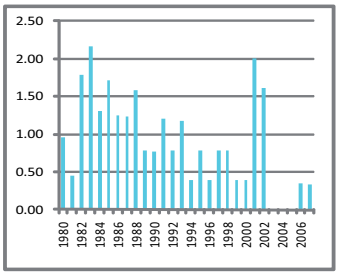
Hypoplastic left heart syndrome



Coarctation of aorta



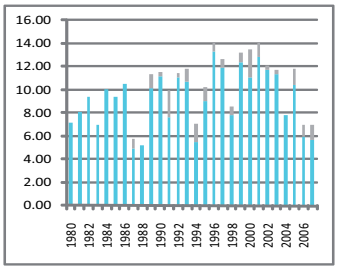
Choanal atresia. bilateral



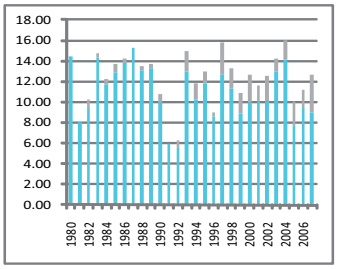
Note: L+S rates, ToP rates

Australia: WABDR

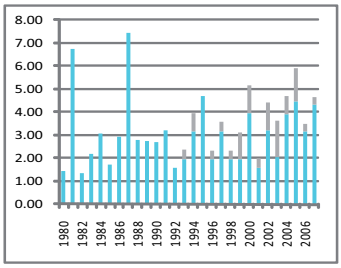
Cleft palate without cleft lip



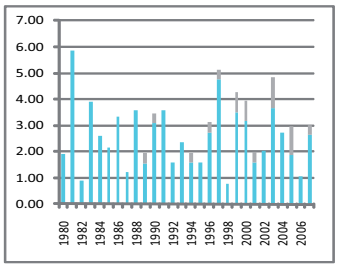
Cleft lip with or without cleft palate



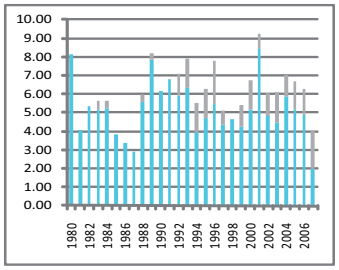
Oesophageal atresia/stenosis with or without fistula



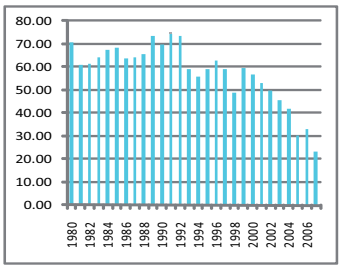
Small intestine atresia/stenosis



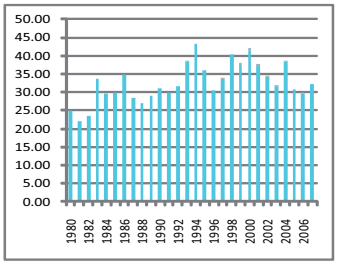
Anorectal atresia/stenosis



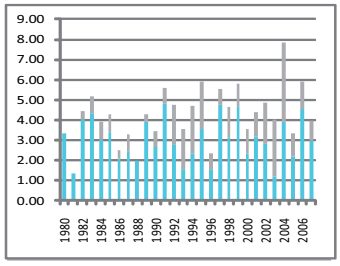
Undescended testis



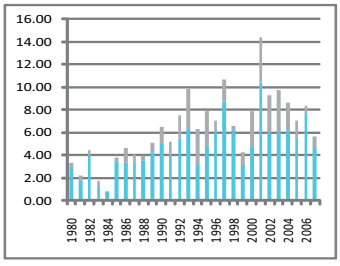
Hypospadias



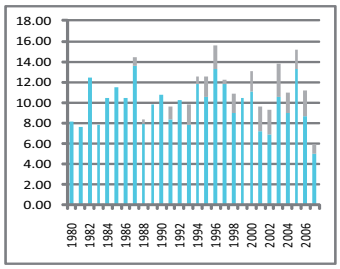
Renal agenesis



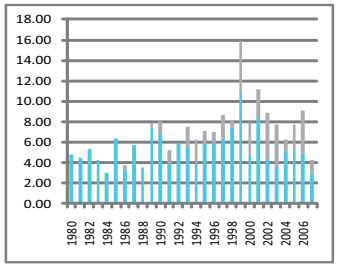
Cystic kidney



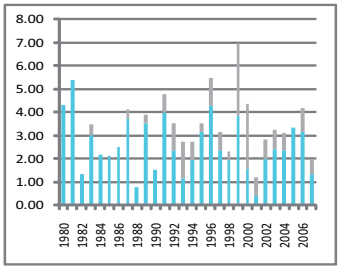
Polydactyly. preaxial



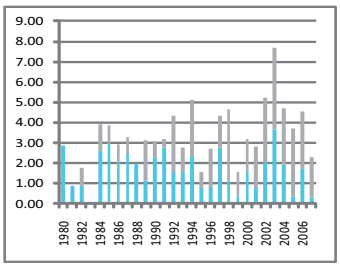
Limb reduction defects



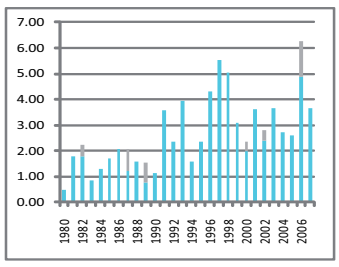
Diaphragmatic hernia



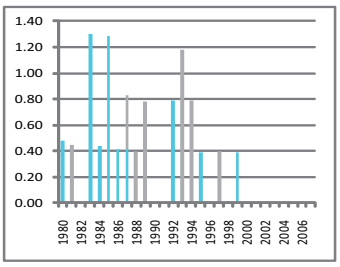
Omphalocele



Gastroschisis



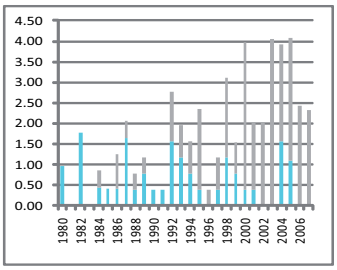
Prune belly sequence



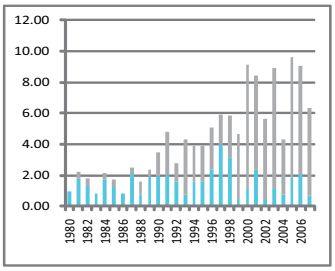
Note: L+S rates, ToP rates

Australia: WABDR

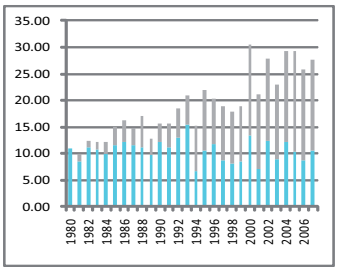
Trisomy 13



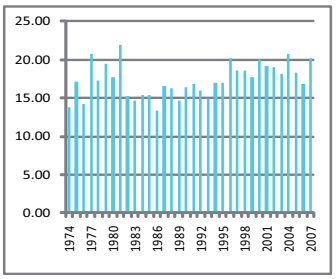
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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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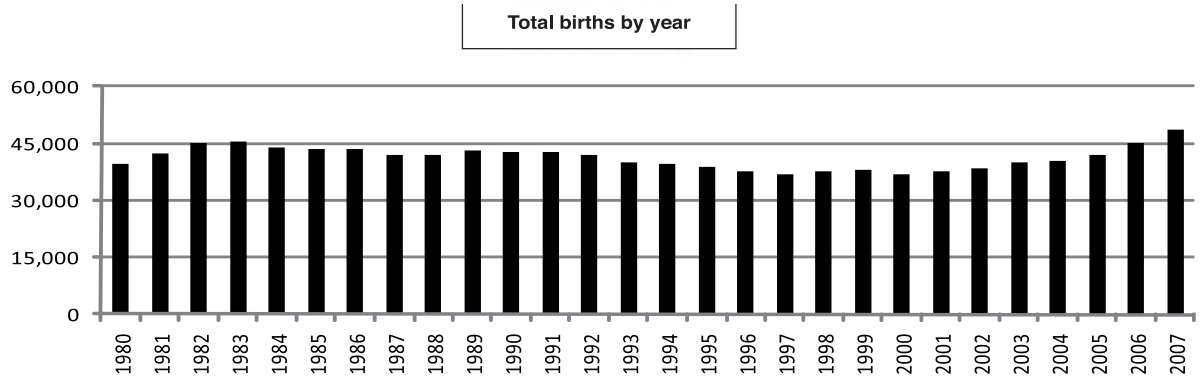
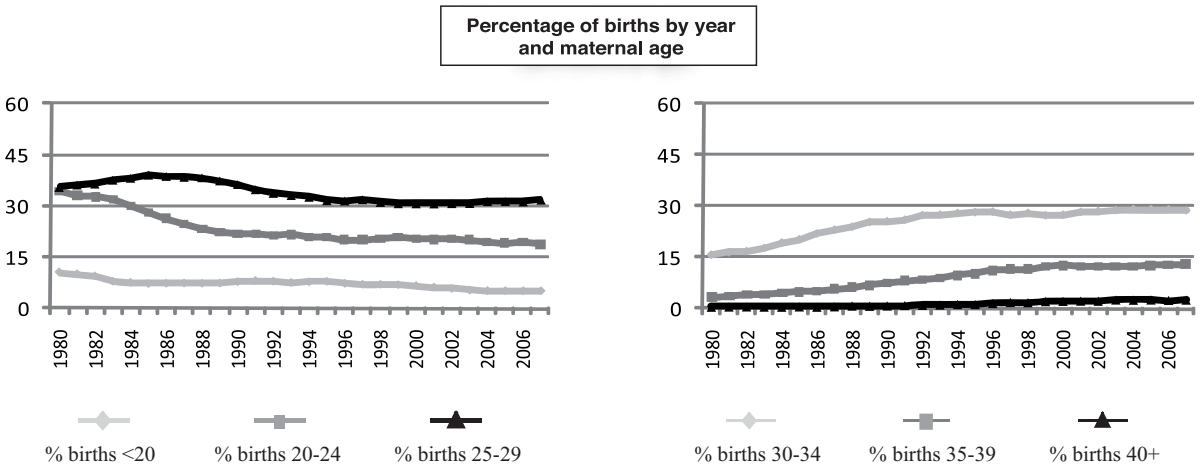
Barbara Sibbald – RN, MSc, Manager
E-mail: barbara.sibbald@calgaryhealtregion.ca

Canada-Alberta: ACASS





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	6	22.2	Cystic kidney	4	3.9
Spina bifida	9	15.5	Limb reduction defects	23	17.4
Encephalocele	5	31.3	Diaphragmatic hernia	3	6.3
Holoprosencephaly	8	32.0	Omphalocele	12	37.5
Hydrocephaly	3	3.4	Gastroschisis	2	2.7
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	17	41.5
Cleft palate without cleft lip	4	4.8	Trisomy 18	28	38.4
Cleft lip with or without cleft palate	8	4.6	Down syndrome	90	28.6
Renal agenesis	4	28.6			

Total ToPs with births defects = 246 (Ratio ToPs/Births: 1.81 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Canada-Alberta: ACASS, 2007

Live births (LB)	48,365
Stillbirths (SB)	343
Total births	48,708
Number of terminations of pregnancy (ToP) for birth defects	90

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	7	0	2	1.85
Spina bifida	13	3	4	4.11
Encephalocele	3	0	2	1.03
Microcephaly	12	3	0	3.08
Holoprosencephaly	6	2	3	2.26
Hydrocephaly	25	4	0	5.95
Anophthalmos	0	0	0	0.00
Microphthalmos	6	1	0	1.44
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.41
Microtia	11	0	0	2.26
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	10	3	0	2.67
Tetralogy of Fallot	14	1	0	3.08
Hypoplastic left heart syndrome	16	2	0	3.70
Coarctation of aorta	19	0	0	3.90
Choanal atresia, bilateral	5	0	0	1.03
Cleft palate without cleft lip	24	1	1	5.34
Cleft lip with or without cleft palate	72	7	2	16.63
Oesophageal atresia/stenosis with or without fistula	5	0	0	1.03
Small intestine atresia/stenosis	5	0	0	1.03
Anorectal atresia/stenosis	10	2	1	2.67
Undescended testis (36 weeks of gestation or later)	130	0	0	26.69
Hypospadias	103	0	0	21.15
Epispadias	4	0	0	0.82
Indeterminate sex	8	2	0	2.05
Renal agenesis	4	0	0	0.82
Cystic kidney	31	4	1	7.39
Bladder exstrophy	2	0	0	0.41
Polydactyly, preaxial	81	3	6	18.48
Total Limb reduction defects (include unspecified)	36	9	6	10.47
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	16	3	0	3.90
Omphalocele	6	3	3	2.46
Gastroschisis	22	2	0	4.93
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.21
Trisomy 13	8	4	8	4.11
Trisomy 18	5	10	8	4.72
Down syndrome, all ages (include age unknown)	70	9	38	24.02
<20	2	0	0	7.99
20-24	5	0	2	7.65
25-29	13	0	3	10.31
30-34	19	2	6	19.34
35-39	19	3	17	61.34
40-44	12	3	9	206.90
45+	0	1	1	400.00
unknown	0	0	0	---

nr = not reported

Canada-Alberta: ACASS, Previous years rates 1980 - 2007

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

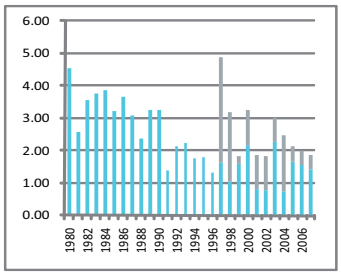
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births		**127,105**	**218,319**	**212,707**	**193,175**	**188,664**	**215,931**
Anencephaly		3.54	3.53	2.49	2.38	2.39	2.27
Spina bifida		4.17	5.45	5.27	5.23	3.07	4.08
Encephalocele		1.02	1.01	0.75	1.24	1.43	1.16
Microcephaly		3.62	3.11	4.18	2.43	3.39	3.94
Holoprosencephaly		0.47	0.55	0.99	1.40	1.80	1.99
Hydrocephaly		6.45	5.73	4.94	5.07	5.09	6.16
Anophthalmos		0.24	0.27	0.52	0.26	0.48	0.19
Microphthalmos		0.79	1.10	1.22	0.93	1.59	1.48
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.00	0.23	0.24	0.26	0.58	0.46
Microtia		0.16	0.64	0.75	1.19	1.22	2.04
Unspecified Anotia / Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		2.83	3.02	2.91	3.57	3.55	3.84
Tetralogy of Fallot		1.34	2.43	3.34	2.43	2.28	2.18
Hypoplastic left heart syndrome		2.44	2.06	2.30	2.12	2.86	3.24
Coarctation of aorta		2.75	4.53	4.51	5.07	2.81	3.43
Choanal atresia, bilateral		0.79	1.37	1.79	1.60	1.80	1.67
Cleft palate without cleft lip		6.29	7.10	7.52	8.33	8.80	6.53
Cleft lip with or without cleft palate		10.31	10.72	12.93	11.23	12.14	12.74
Oesophageal atresia / stenosis with or without fistula		2.28	2.93	3.10	1.97	2.49	2.08
Small intestine atresia / stenosis		0.79	0.82	1.32	1.55	2.07	1.20
Anorectal atresia / stenosis		3.15	4.12	5.27	5.28	6.41	4.82
Undescended testis (36 weeks of gestation or later)		26.04	26.84	30.28	23.09	24.01	26.12
Hypospadias		16.76	20.98	25.10	20.60	18.76	21.16
Epispadias		0.71	0.27	0.38	0.41	0.58	0.79
Indeterminate sex		0.24	0.50	0.99	0.88	1.54	1.62
Renal agenesis		2.44	2.52	2.40	1.24	1.70	1.30
Cystic kidney		1.89	2.66	5.31	5.33	6.31	8.20
Bladder exstrophy		0.39	0.23	0.28	0.31	0.42	0.37
Polydactyly, preaxial		10.23	11.08	15.98	13.77	12.99	18.43
'Total Limb reduction defects (include unspecified)		5.82	7.37	11.14	8.54	13.20	10.65
Transverse		nr	nr	nr	nr	nr	nr
Preaxial		nr	nr	nr	nr	nr	nr
Postaxial		nr	nr	nr	nr	nr	nr
Intercalary		nr	nr	nr	nr	nr	nr
Mixed		nr	nr	nr	nr	nr	nr
Unspecified		nr	nr	nr	nr	nr	nr
Diaphragmatic hernia		3.23	3.62	2.59	2.48	4.45	3.29
Omphalocele		1.18	2.15	2.44	1.81	2.33	2.59
Gastroschisis		1.57	1.51	1.46	2.12	2.86	4.72
Unspecified Omphalocele / Gastroschisis		0.87	0.32	0.52	0.16	0.00	0.00
Prune belly sequence		0.71	0.23	0.28	0.21	0.32	0.51
Trisomy 13		0.79	0.69	1.18	1.04	1.70	2.78
Trisomy 18		1.34	1.74	1.93	3.05	4.45	4.82
Down syndrome, all ages (include age unknown)		9.28	9.21	10.67	11.75	18.07	22.65
<20		nr	3.21*	5.53	3.46	9.77	9.81
20-24		nr	4.61*	6.99	5.74	3.89	8.14
25-29		nr	6.39*	6.12	7.38	11.15	10.62
30-34		nr	9.42*	14.36	13.40	15.05	17.19
35-39		nr	46.92*	25.15	29.11	46.79	56.79
40-44		nr	149.57*	93.20	80.00	156.21	195.50
45+		nr	0.00*	289.86	263.16	225.56	436.68
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

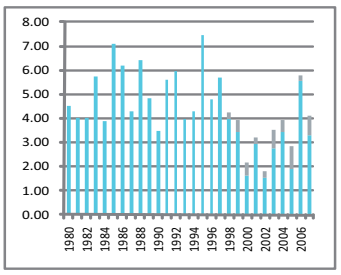
Canada-Alberta: ACASS

'Time trends 1980-2007 (Birth prevalence rates per 10,000)

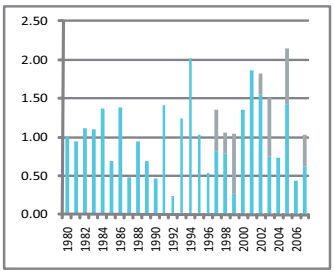
Anencephaly



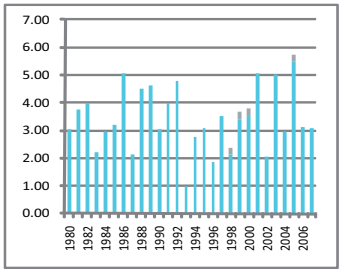
Spina Bifida



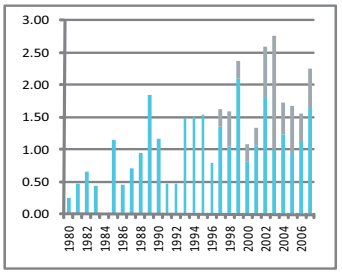
Encephalocele



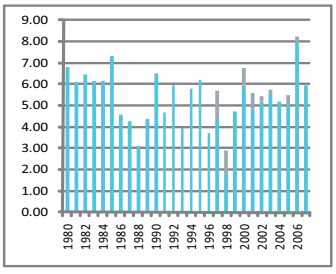
Microcephaly



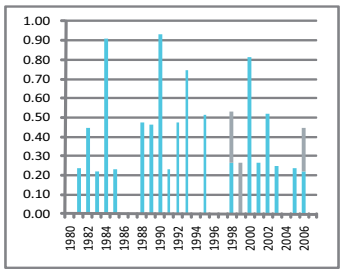
Holoprosencephaly



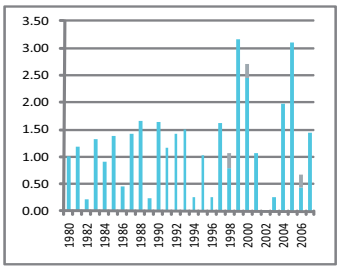
Hydrocephaly



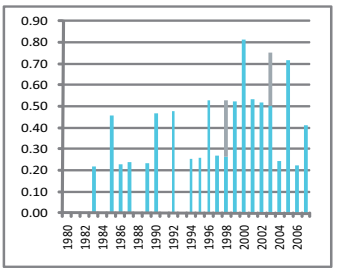
Anophthalmos



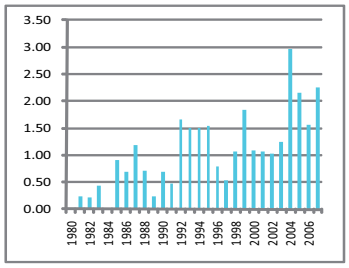
Microphthalmos



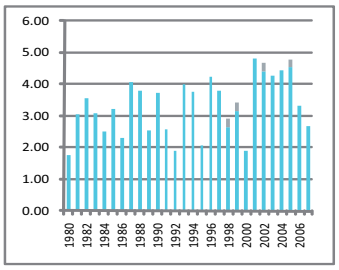
Anotia



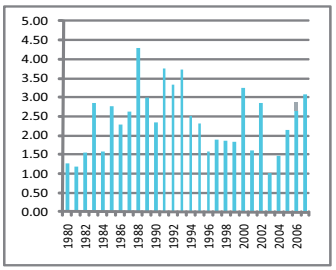
Microtia



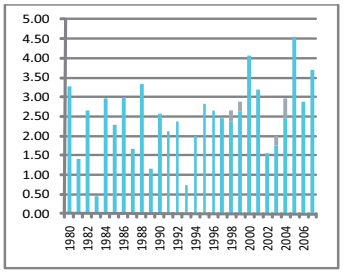
Transposition of great vessels



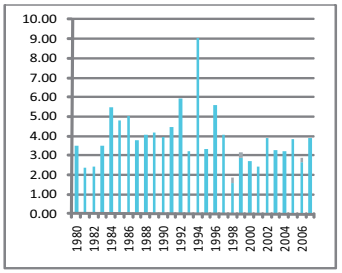
Tetralogy of Fallot



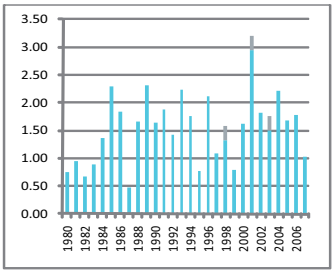
Hypoplastic left heart syndrome



Coarctation of aorta



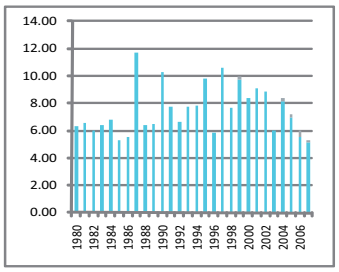
Choanal atresia. bilateral



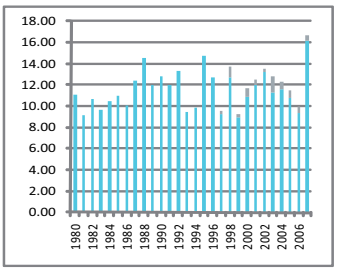
Note: L+S rates, ToP rates

Canada-Alberta: ACASS

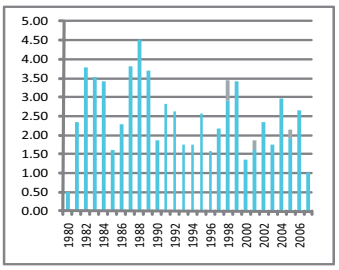
Cleft palate without cleft lip



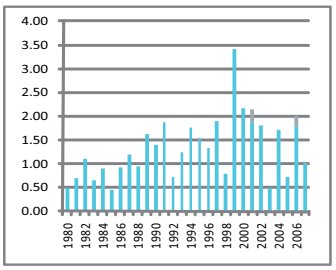
Cleft lip with or without cleft palate



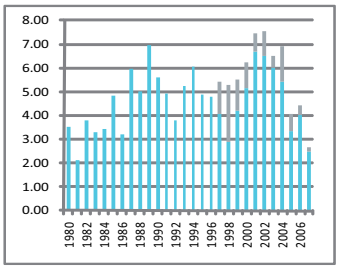
Oesophageal atresia/stenosis with or without fistula



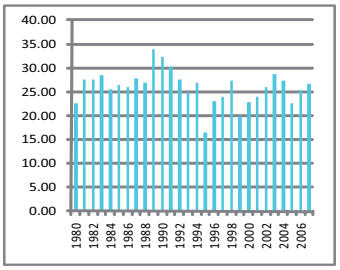
Small intestine atresia/stenosis



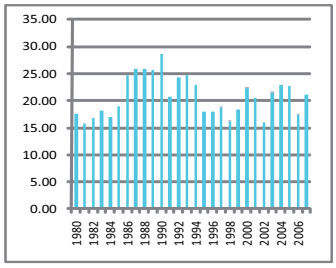
Anorectal atresia/stenosis



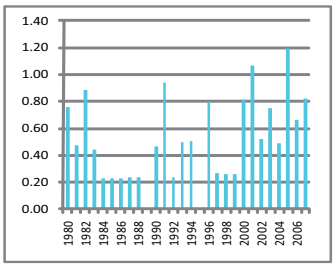
Undescended testis



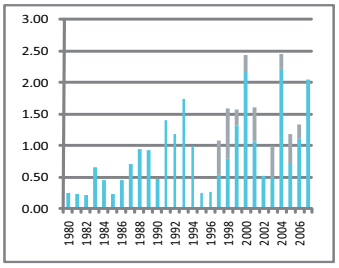
Hypospadias



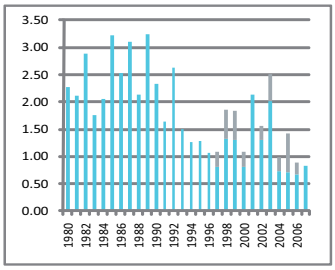
Epispadias



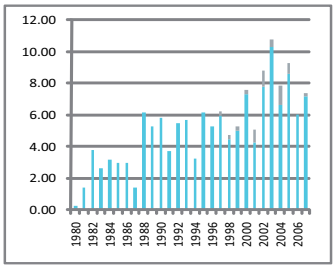
Indeterminate sex



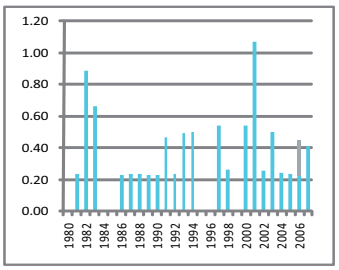
Renal agenesis



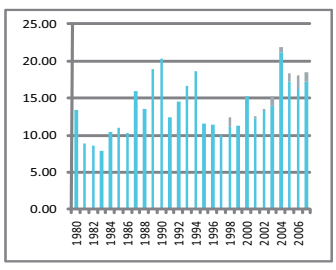
Cystic kidney



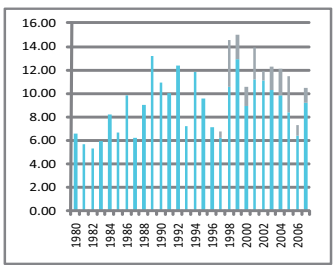
Bladder exstrophy



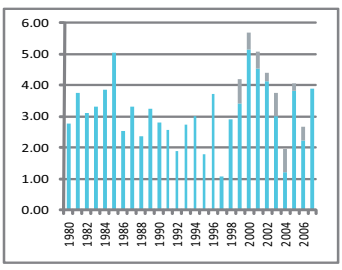
Polydactyly, preaxial



Limb reduction defects



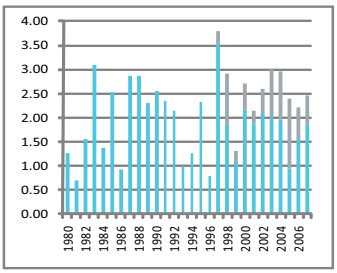
Diaphragmatic hernia



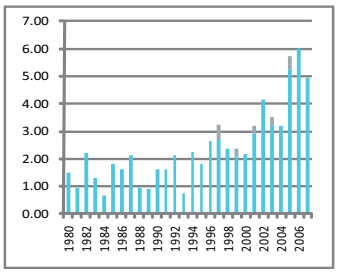
Note: L+S rates, ToP rates

Canada-Alberta: ACASS

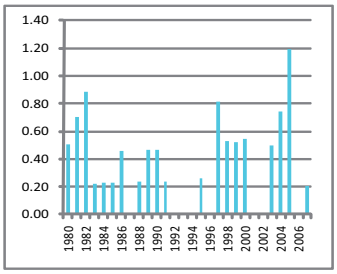
Omphalocele



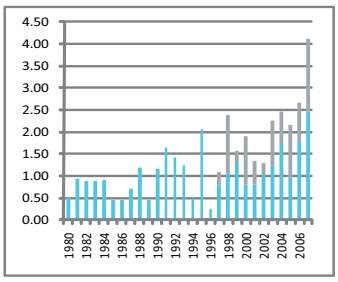
Gastroschisis



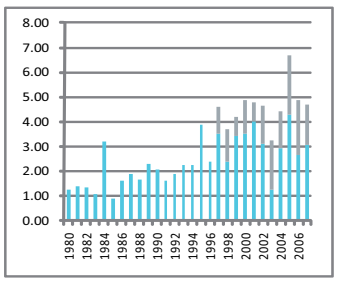
Prune belly sequence



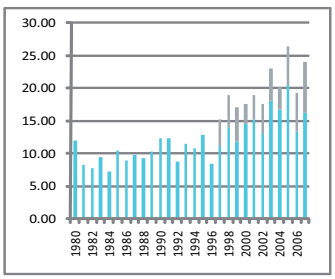
Trisomy 13



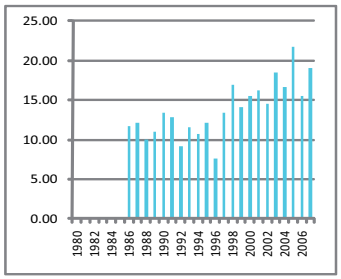
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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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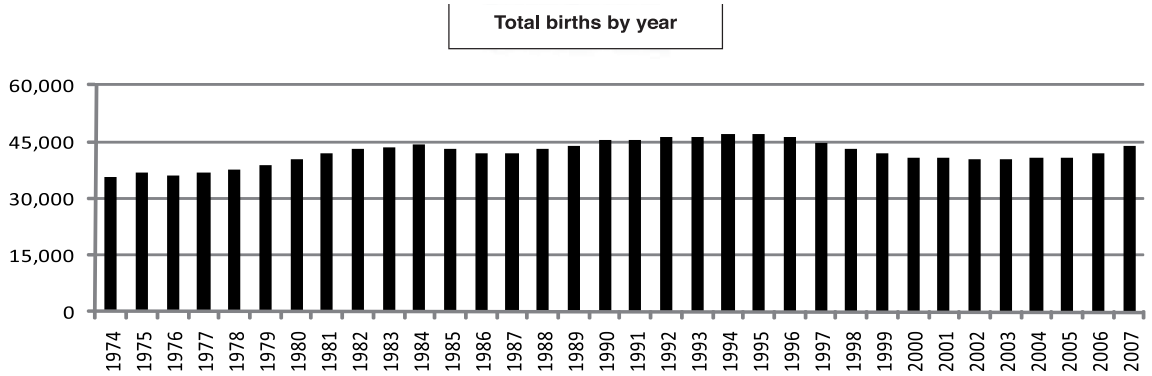
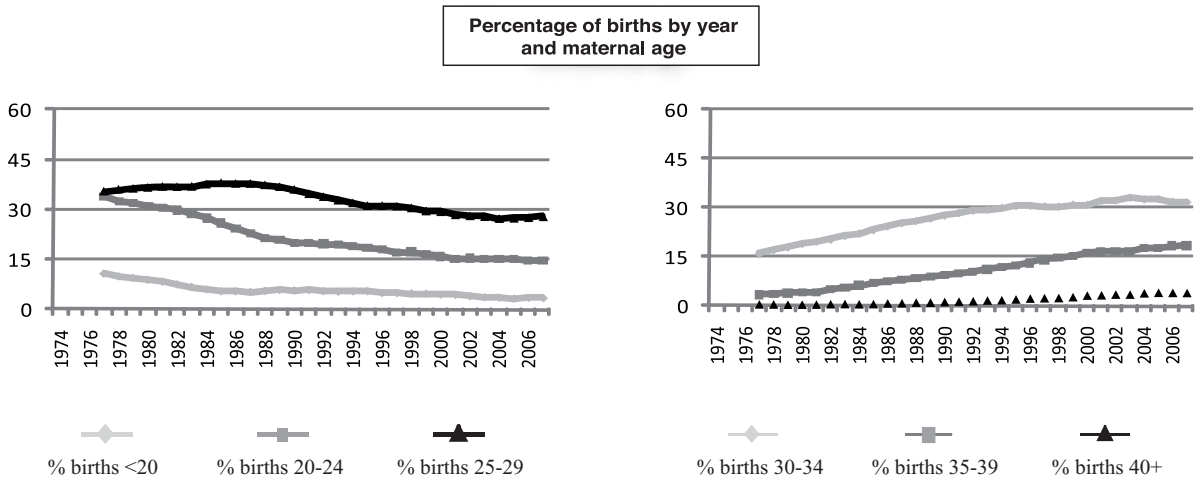
British Columbia, CANADA, V8W 3C8

Canada: British Columbia





Canada: British Columbia, 2007

Live births (LB)	43,522
Stillbirths (SB)	356
Total births	43,878
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	1	nr	0.46
Spina bifida	12	4	nr	3.65
Encephalocele	1	0	nr	0.23
Microcephaly	17	0	nr	3.87
Holoprosencephaly	37	10	nr	10.71
Hydrocephaly	15	4	nr	4.33
Anophthalmos	2	1	nr	0.68
Microphthalmos	5	0	nr	1.14
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia 0	0	nr	0.00	
Microtia	7	1	nr	1.82
Unspecified Anotia/Microtia	9	2	nr	2.51
Transposition of great vessels	14	1	nr	3.42
Tetralogy of Fallot	19	0	nr	4.33
Hypoplastic left heart syndrome	6	2	nr	1.82
Coarctation of aorta	32	0	nr	7.29
Choanal atresia, bilateral	8	0	nr	1.82
Cleft palate without cleft lip	48	0	nr	10.94
Cleft lip with or without cleft palate	21	6	nr	6.15
Oesophageal atresia/stenosis with or without fistula	12	0	nr	2.73
Small intestine atresia/stenosis	24	1	nr	5.70
Anorectal atresia/stenosis	23	0	nr	5.24
Undescended testis (36 weeks of gestation or later)	186	0	nr	42.39
Hypospadias	124	0	nr	28.26
Epispadias	6	0	nr	1.37
Indeterminate sex	0	0	nr	0.00
Renal agenesis	3	1	nr	0.91
Cystic kidney	4	0	nr	0.91
Bladder exstrophy	4	1	nr	1.14
Polydactyly, preaxial	54	2	nr	12.76
Total Limb reduction defects (include unspecified)	15	2	nr	3.87
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	14	2	nr	3.65
Omphalocele	15	0	nr	3.42
Gastroschisis	21	1	nr	5.01
Unspecified Omphalocele/Gastroschisis	2	0	nr	0.46
Prune belly sequence	0	1	nr	0.23
Trisomy 13	0	7	nr	1.60
Trisomy 18	4	12	nr	3.65
Down syndrome, all ages (include age unknown)	44	26	nr	15.95
<20	1	1	nr	13.45
20-24	7	2	nr	13.96
25-29	5	2	nr	5.72
30-34	12	5	nr	12.25
35-39	14	13	nr	33.42
40-44	4	2	nr	36.45
45+	0	1	nr	98.04
unknown	1	0	nr	---

nr = not reported

Canada: British Columbia, Previous years rates 1974 - 2007

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

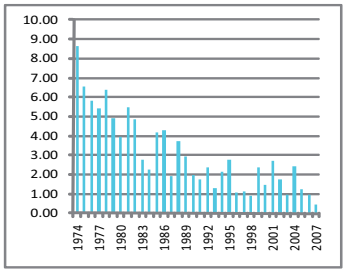
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**145,739**	**202,036**	**214,942**	**224,683**	**231,416**	**206,834**	**208,304**
Anencephaly	6.59	5.10	3.07	2.54	1.69	1.84	1.20
Spina bifida	11.66	8.41	7.72	7.83	5.57	4.21	3.22
Encephalocele	1.72	1.68	1.30	2.00	1.08	0.58	0.38
Microcephaly	4.67	5.54	6.65	7.21	8.94	6.62	4.99
Holoprosencephaly	1.58	2.52	5.02	4.14	4.19	8.61	10.85
Hydrocephaly	10.02	11.09	6.19	7.17	6.40	4.88	3.41
Anophthalmos	0.34	0.59	0.28	0.58	0.22	0.29	0.34
Microphthalmos	1.65	1.63	1.67	1.56	1.64	1.84	0.67
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	3.22	2.23	3.35	2.54	2.25	1.40	0.14
Microtia	31.77	51.82	65.13	41.57	17.80	4.21	0.67
Unspecified Anotia / Microtia	2.06	2.92	1.91	2.09	1.25	1.64	1.20
Transposition of great vessels	4.32	4.80	4.75	4.90	5.27	4.45	3.12
Tetralogy of Fallot	5.08	5.25	6.05	5.43	4.11	5.08	3.98
Hypoplastic left heart syndrome	1.72	2.92	2.74	2.58	2.68	3.43	2.16
Coarctation of aorta	5.42	7.57	6.84	6.54	5.83	6.24	4.90
Choanal atresia, bilateral	1.10	1.68	2.00	1.82	1.77	2.71	1.34
Cleft palate without cleft lip	11.25	10.20	11.58	14.78	11.93	9.86	7.78
Cleft lip with or without cleft palate	14.48	14.50	15.21	14.46	13.53	12.38	6.77
Oesophageal atresia / stenosis with or without fistula	3.16	3.37	4.05	3.20	3.37	3.29	2.26
Small intestine atresia / stenosis	2.13	2.87	3.68	3.38	3.98	4.16	4.61
Anorectal atresia / stenosis	4.87	4.36	4.56	5.52	4.97	5.56	5.33
Undescended testis (36 weeks of gestation or later)	74.31	73.16	73.88	72.15	58.16	48.20	25.68
Hypospadias	26.55	30.89	32.57	37.12	36.69	29.49	19.25
Epispadias	0.00	0.00	0.05	0.00	0.00	0.19	0.67
Indeterminate sex	0.75	1.48	1.26	0.85	1.25	0.82	0.00
Renal agenesis	5.01	5.69	6.79	7.21	5.44	4.54	0.48
Cystic kidney	3.43	3.51	5.68	5.92	6.70	4.64	0.43
Bladder exstrophy	0.41	0.45	0.56	0.53	0.30	0.48	0.48
Polydactyly, preaxial	23.19	22.12	20.70	23.81	20.66	18.57	9.17
‘Total Limb reduction defects (include unspecified)	10.29	9.50	7.77	7.70	6.18	4.64	3.26
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	4.53	4.55	3.63	3.87	4.54	3.38	3.41
Omphalocele	0.00	0.00	0.05	0.00	0.09	1.35	2.40
Gastroschisis	0.00	0.00	0.00	0.04	0.17	2.80	4.56
Unspecified Omphalocele / Gastroschisis	29.78	22.32	10.10	7.39	8.30	5.80	0.77
Prune belly sequence	0.00	0.00	0.05	0.00	0.04	0.10	0.24
Trisomy 13	0.69	0.45	1.16	1.11	1.25	1.35	1.49
Trisomy 18	1.24	2.03	2.05	2.00	2.72	4.21	3.60
Down syndrome, all ages (include age unknown)	12.01	13.46	14.42	15.13	17.50	17.02	16.75
<20	2.53*	7.37	8.84	10.21	9.97	9.74	6.93
20-24	4.78*	6.05	5.57	8.98	8.44	9.32	7.73
25-29	7.63*	7.33	7.94	5.62	10.12	10.42	8.17
30-34	11.79*	15.67	14.37	14.83	15.74	13.76	12.20
35-39	15.63*	37.62	24.09	22.21	26.01	28.60	32.21
40-44	150.75*	84.67	102.11	63.29	73.85	62.84	69.03
45+	434.78*	0.00	327.87	92.59	711.11	75.47	137.30
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 4 years

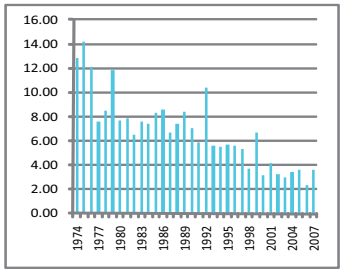
Canada: British Columbia

Time trends 1974-2007 (Birth prevalence rates per 10,000)

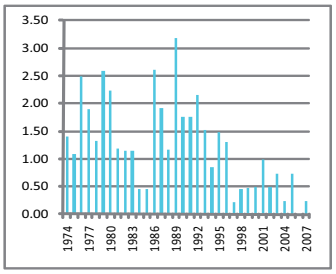
Anencephaly



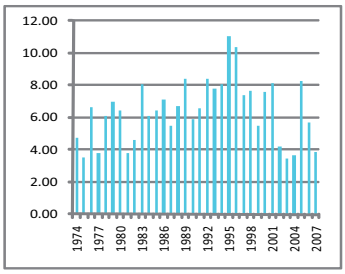
Spina Bifida



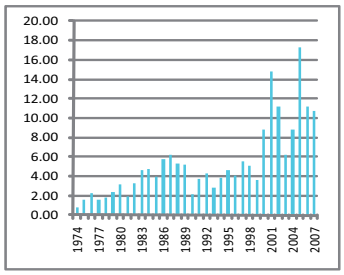
Encephalocele



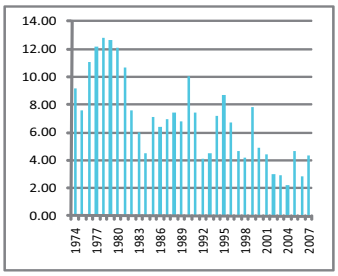
Microcephaly



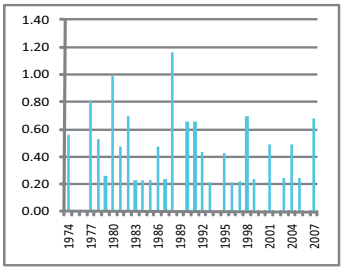
Holoprosencephaly



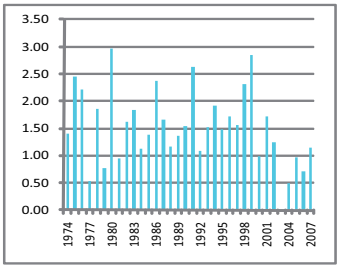
Hydrocephaly



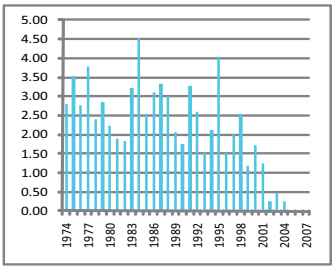
Anophthalmos



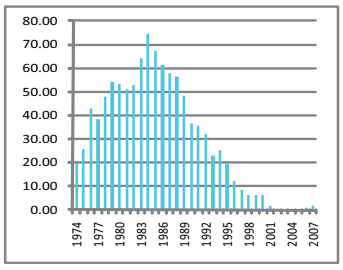
Microphthalmos



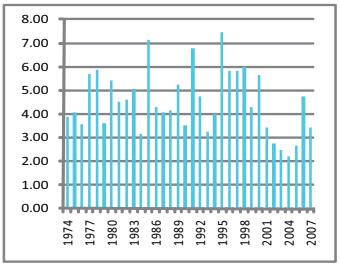
Anotia



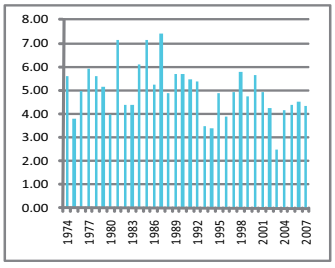
Microtia



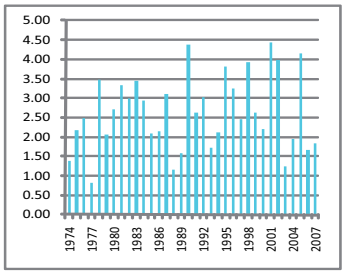
Transposition of great vessels



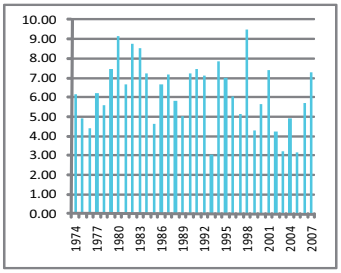
Tetralogy of Fallot



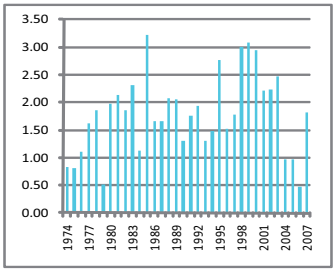
Hypoplastic left heart syndrome



Coarctation of aorta



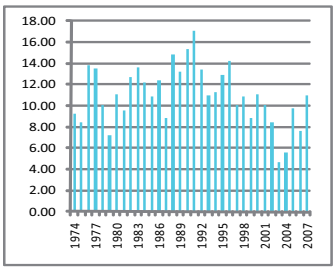
Choanal atresia. bilateral



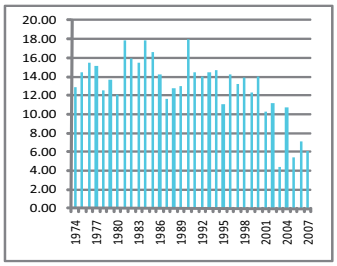
Note: L+S rates

Canada: British Columbia

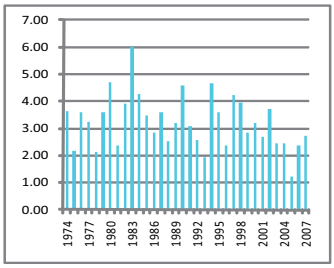
Cleft palate without cleft lip



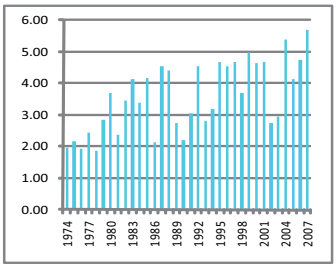
Cleft lip with or without cleft palate



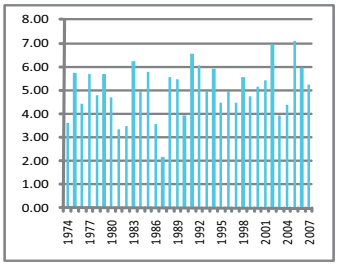
Oesophageal atresia/stenosis with or without fistula



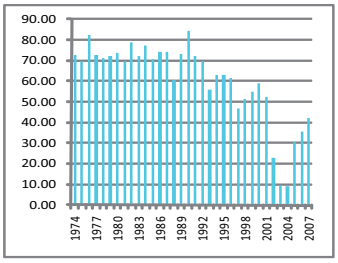
Small intestine atresia/stenosis



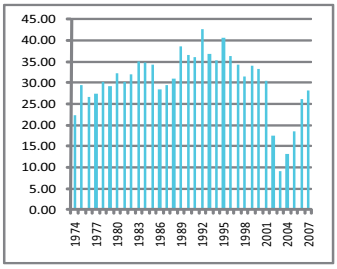
Anorectal atresia/stenosis



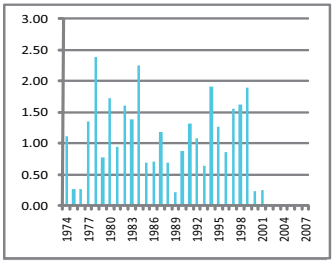
Undescended testis



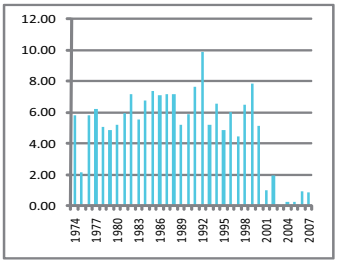
Hypospadias



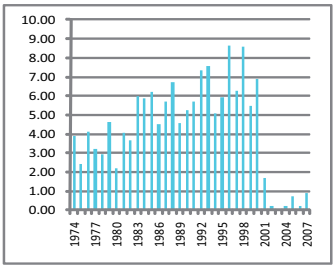
Indeterminate sex



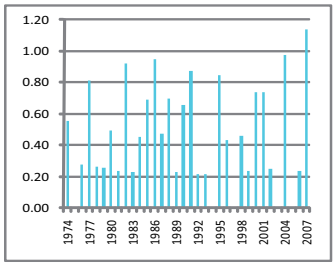
Renal agenesis



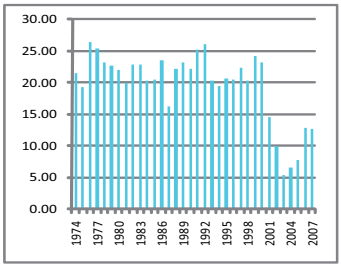
Cystic kidney



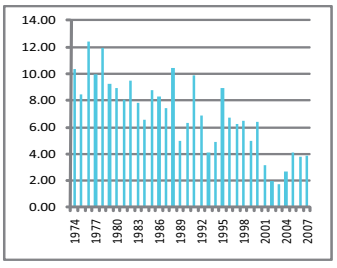
Bladder exstrophy



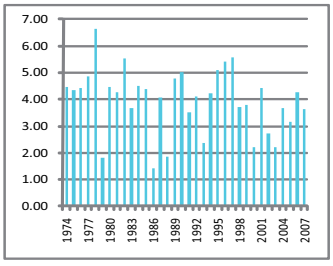
Polydactyly, preaxial



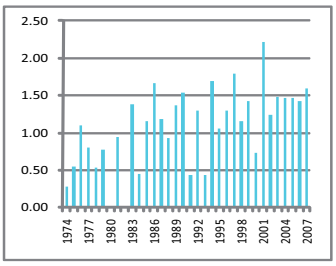
Limb reduction defects



Diaphragmatic hernia



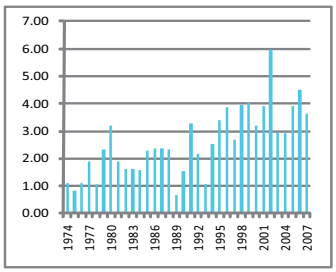
Trisomy 13



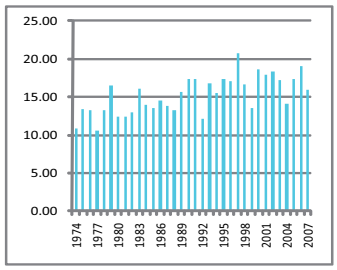
Note: L+S rates

Canada: British Columbia

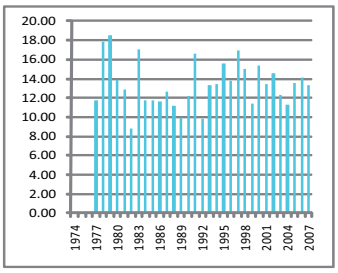
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S 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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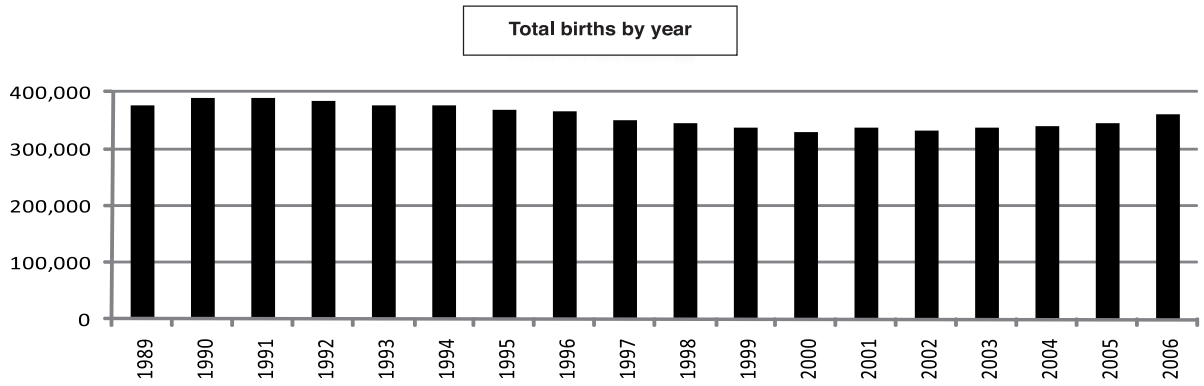
Canada: National



Canada: National, 2006

Live births (LB)	357,208
Stillbirths (SB)	2,410
Total births	359,618
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	14	14	nr	0.78
Spina bifida	70	20	nr	2.50
Encephalocele	11	2	nr	0.36
Microcephaly	104	3	nr	2.98
Holoprosencephaly	9	3	nr	0.33
Hydrocephaly	141	17	nr	4.39
Anophthalmos	2	0	nr	0.06
Microphthalmos	3	1	nr	0.11
Unspecified Anophthalmos/Microphthalmos	5	1	nr	0.17
Anotia	5	0	nr	0.14
Microtia	23	0	nr	0.64
Unspecified Anotia/Microtia	27	0	nr	0.75
Transposition of great vessels	166	6	nr	4.78
Tetralogy of Fallot	138	2	nr	3.89
Hypoplastic left heart syndrome	73	6	nr	2.20
Coarctation of aorta	178	1	nr	4.98
Choanal atresia, bilateral	68	0	nr	1.89
Cleft palate without cleft lip	227	3	nr	6.40
Cleft lip with or without cleft palate	304	10	nr	8.73
Oesophageal atresia/stenosis with or without fistula	106	0	nr	2.95
Small intestine atresia/stenosis	124	3	nr	3.53
Anorectal atresia/stenosis	149	0	nr	4.14
Undescended testis (36 weeks of gestation or later) (*)	1,236	0	nr	34.37
Hypospadias	861	0	nr	23.94
Epispadias	19	0	nr	0.53
Indeterminate sex	34	1	nr	0.97
Renal agenesis	167	10	nr	4.92
Cystic kidney	234	10	nr	6.78
Bladder exstrophy	12	2	nr	0.39
Polydactyly, preaxial	497	1	nr	13.85
Total Limb reduction defects (include unspecified)	112	2	nr	3.17
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	nr	nr	nr	nr
Diaphragmatic hernia	101	9	nr	3.06
Omphalocele	51	12	nr	1.75
Gastroschisis	127	7	nr	3.73
Unspecified Omphalocele/Gastroschisis	176	19	nr	5.42
Prune belly sequence	0	0	nr	0.00
Trisomy 13	17	14	nr	0.86
Trisomy 18	39	42	nr	2.25
Down syndrome, all ages (include age unknown)	453	61	nr	14.29
<20	nr	nr	nr	nr
20-24	nr	nr	nr	nr
25-29	nr	nr	nr	nr
30-34	nr	nr	nr	nr
35-39	nr	nr	nr	nr
40-44	nr	nr	nr	nr
45+	nr	nr	nr	nr
unknown	nr	nr	nr	---

nr = not reported
(*) No information regarding gestation

Canada: National, Previous years rates 2006

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

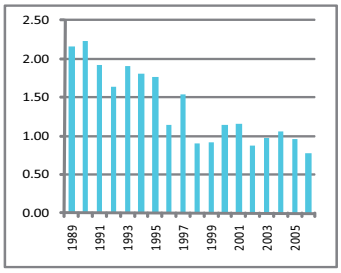
	1974-1981	1982-19861987-1991*	1992-1996	1997-2001	2002-2006
Total births		**1,156,605**	**1,872,269**	**1,700,602**	**1,714,148**
Anencephaly		2.10	1.66	1.13	0.93
Spina bifida		7.58	6.30	4.10	2.91
Encephalocele		1.38	1.29	0.82	0.55
Microcephaly		5.78	5.11	5.69	4.56
Holoprosencephaly		nr	nr	nr	0.33*
Hydrocephaly		7.31	6.80	6.60	4.79
Anophthalmos		0.34	0.28	0.28	0.54
Microphthalmos		1.15	0.87	1.06	0.26
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.16
Anotia		nr	nr	nr	0.13*
Microtia		nr	nr	nr	0.63*
Unspecified Anotia / Microtia		nr	nr	nr	0.75*
Transposition of great vessels		4.51	4.96	5.41	4.95
Tetralogy of Fallot		4.87	4.62	5.12	3.98
Hypoplastic left heart syndrome		3.03	2.78	2.98	2.51
Coarctation of aorta		5.20	5.74	6.13	4.86
Choanal atresia, bilateral		2.08	2.06	2.80	2.44
Cleft palate without cleft lip		7.20	6.96	7.48	7.01
Cleft lip with or without cleft palate		11.54	11.05	10.60	9.21
Oesophageal atresia / stenosis with or without fistula		3.57	3.18	3.43	3.02
Small intestine atresia / stenosis		3.55	3.42	3.73	3.77
Anorectal atresia / stenosis		5.48	4.86	4.89	4.37
Undescended testis (36 weeks of gestation or later)		35.69	32.86	33.45	35.96
Hypospadias		27.11	26.36	27.74	28.28
Epispadias		nr	nr	nr	0.52*
Indeterminate sex		0.78	0.60	0.76	1.10
Renal agenesis		4.98	4.94	5.05	5.08
Cystic kidney		4.44	5.43	6.39	7.03
Bladder exstrophy		0.45	0.38	0.37	0.41
Polydactyly, preaxial		12.44	11.39	12.64	14.23
‘Total Limb reduction defects (include unspecified)		4.80	4.49	4.00	3.63
Transverse		nr	nr	nr	nr
Preaxial		nr	nr	nr	nr
Postaxial		nr	nr	nr	nr
Intercalary		nr	nr	nr	nr
Mixed		nr	nr	nr	nr
Unspecified		nr	nr	nr	nr
Diaphragmatic hernia		3.59	3.75	3.64	3.28
Omphalocele		4.51	6.19	nr	1.75*
Gastroschisis		nr	nr	nr	3.72*
Unspecified Omphalocele / Gastroschisis		nr	6.62	6.54	6.05
Prune belly sequence		nr	nr	nr	3.00*
Trisomy 13		1.23	1.09	1.21	1.07
Trisomy 18		2.16	2.21	2.40	2.28
Down syndrome, all ages (include age unknown)		13.65	12.57	14.36	14.64
<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

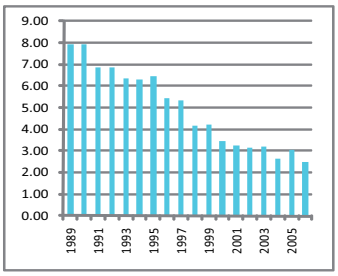
Canada: National

Time trends 1989-2006 (Birth prevalence rates per 10,000)

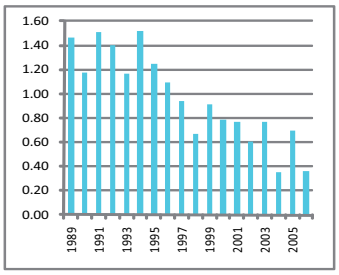
Anencephaly



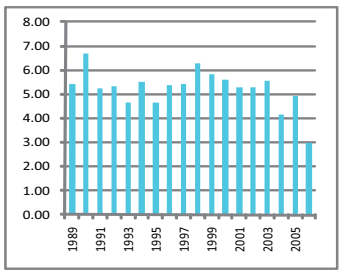
Spina Bifida



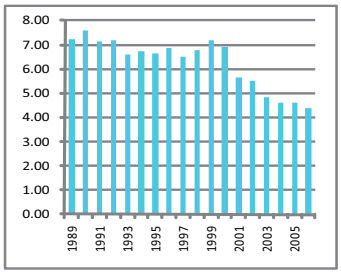
Encephalocele



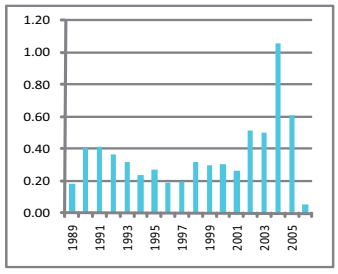
Microcephaly



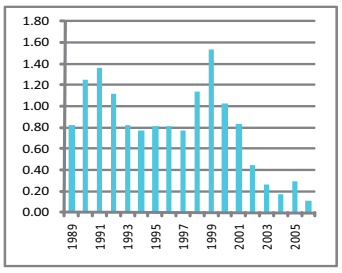
Hydrocephaly



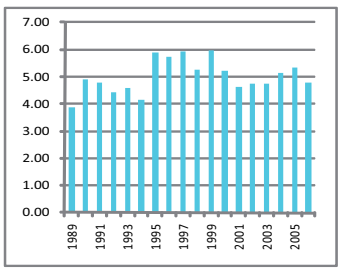
Anophthalmos



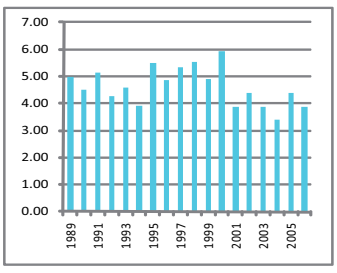
Microphthalmos



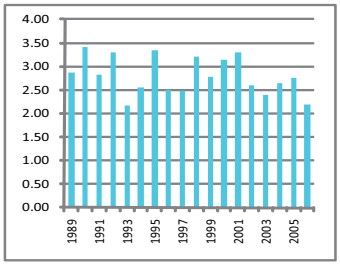
Transposition of great vessels



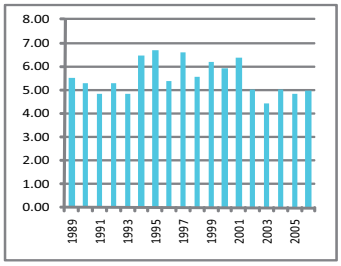
Tetralogy of Fallot



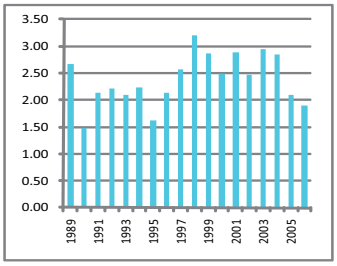
Hypoplastic left heart syndrome



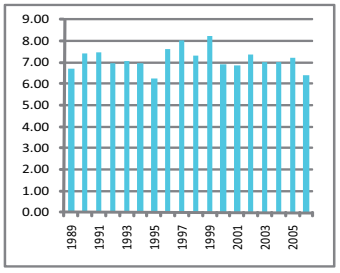
Coarctation of aorta



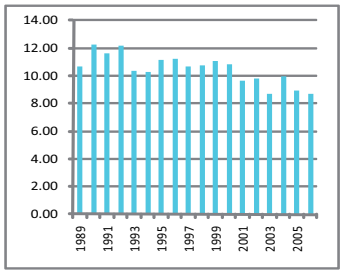
Choanal atresia, bilateral



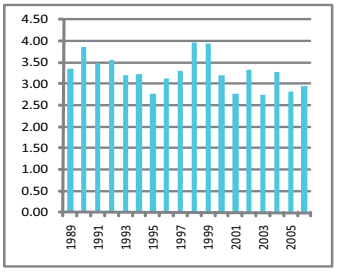
Cleft palate without cleft lip



Cleft lip with or without cleft palate



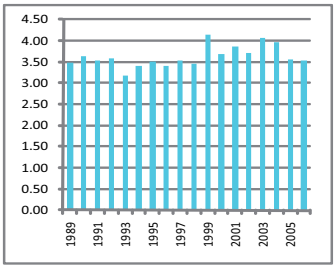
Oesophageal atresia/stenosis with or without fistula



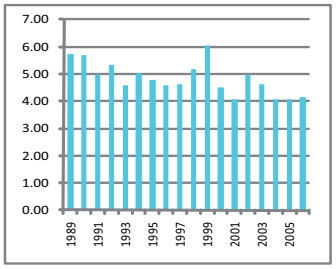
Note: L+S rates

Canada: National

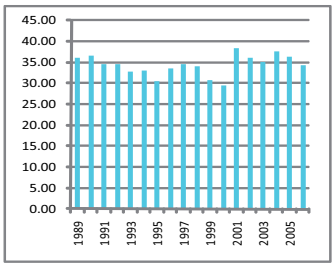
Small intestine atresia/stenosis



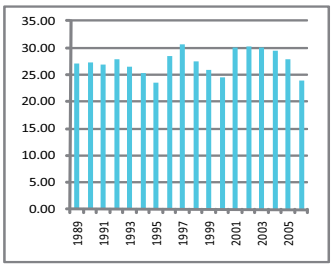
Anorectal atresia/stenosis



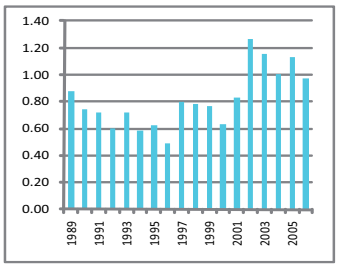
Undescended testis



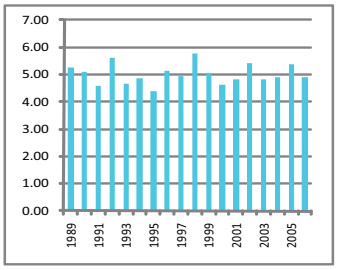
Hypospadias



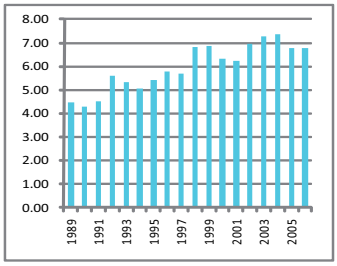
Indeterminate sex



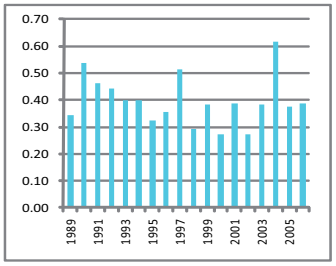
Renal agenesis



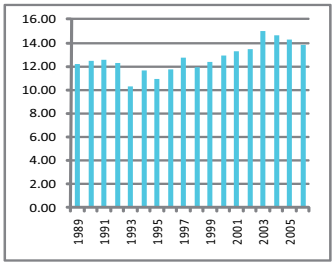
Cystic kidney



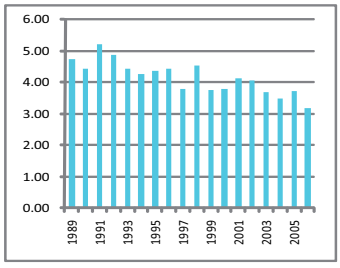
Bladder exstrophy



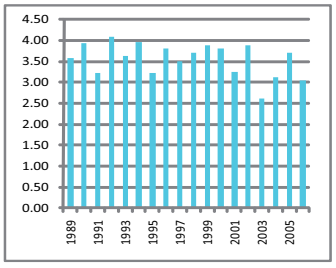
Polydactyly, preaxial



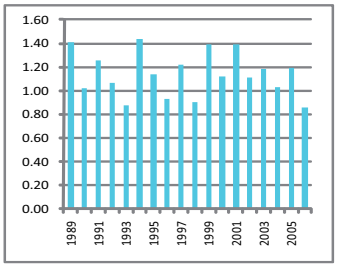
Limb reduction defects



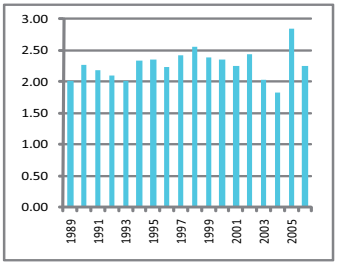
Diaphragmatic hernia



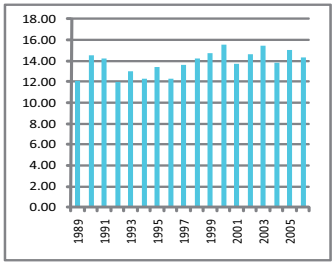
Trisomy 13



Trisomy 18



Down Syndrome



Note: L+S rates

Chile, Maule: RRMC-SSM

Regional Register Congenital Malformational Maule Health Service

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

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

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

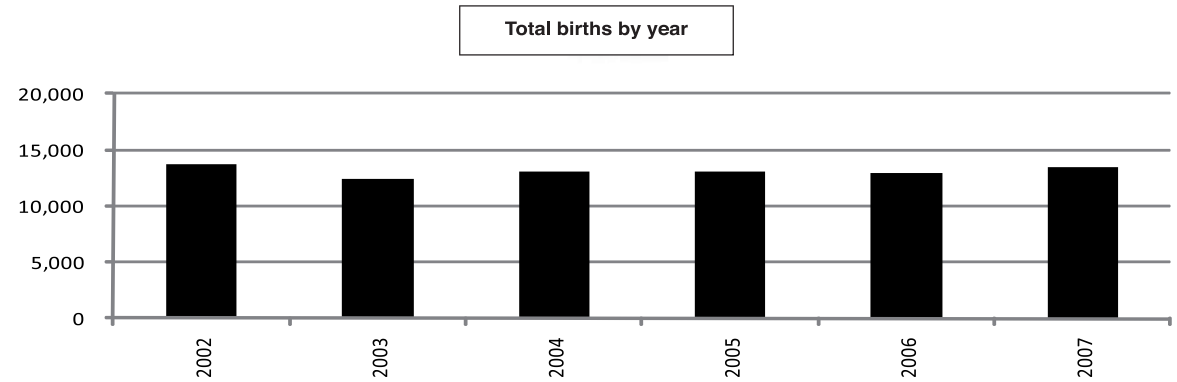
Sources of ascertainment:
Reporting is made by collaborating pediatricians and midwives at the delivery units of participating hospitals.

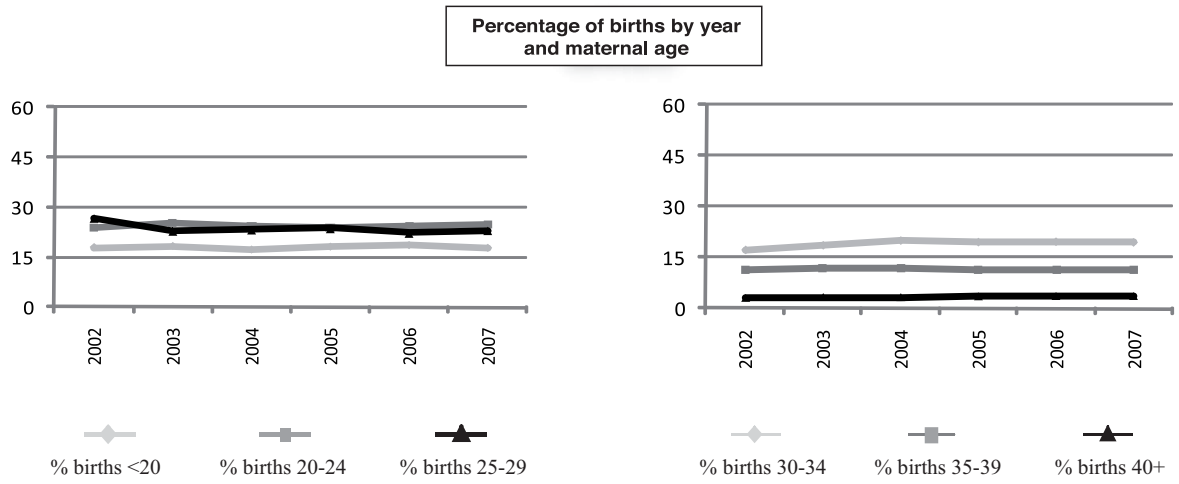
Exposure information:
Detailed information on various risk factor exposures, maternal and paternal occupation, diseases and other information available.

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

Addresses and Staff:
Maria Aurora Canessa,
Linares Hospital
Maule Region
Av. Brazil 753, Linares, Chile.
Phone: 56-73-563276, 56-73-219879.
Fax: 56-73-219111, 56-73-219879.
E-mail: rrmc@ssmaule.cl

Chile: Maule, RRMC-SSM





Chile-Maule: RRMC-SSM, 2007

Live births (LB)	13,305
Stillbirths (SB)	121
Total births	13,426
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	2		1.49
Spina bifida	2	0		1.49
Encephalocele	2	0		1.49
Microcephaly	0	0		0.00
Holoprosencephaly	0	0		0.00
Hydrocephaly	2	2		2.98
Anophthalmos	0	0		0.00
Microphthalmos	1	0		0.74
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	0	0		0.00
Microtia	4	0		2.98
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	1	0		0.74
Tetralogy of Fallot	2	0		1.49
Hypoplastic left heart syndrome	2	0		1.49
Coarctation of aorta	0	0		0.00
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	2	0		1.49
Cleft lip with or without cleft palate	11	1		8.94
Oesophageal atresia/stenosis with or without fistula	0	0		0.00
Small intestine atresia/stenosis	0	1		0.74
Anorectal atresia/stenosis	8	0		5.96
Undescended testis (36 weeks of gestation or later)	15	0		11.17
Hypospadias	11	0		8.19
Epispadias	0	0		0.00
Indeterminate sex	0	0		0.00
Renal agenesis	0	0		0.00
Cystic kidney	1	0		0.74
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	27	1		20.86
Total Limb reduction defects (include unspecified)	13	0		9.68
Transverse	8	0		5.96
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	0	0		0.00
Mixed	0	0		0.00
Unspecified	5	0		3.72
Diaphragmatic hernia	3	0		2.23
Omphalocele	0	1		0.74
Gastroschisis	3	0		2.23
Unspecified Omphalocele/Gastroschisis	1	2		2.23
Prune belly sequence	1	0		0.74
Trisomy 13	0	0		0.00
Trisomy 18	3	0		2.23
Down syndrome, all ages (include age unknown)	33	0		24.58
<20	4	0		16.91
20-24	2	0		6.04
25-29	4	0		12.91
30-34	3	0		11.53
35-39	9	0		58.25
40-44	11	0		236.05
45+	0	0		0.00
unknown	0	0		---

Chile-Maule: RRMC-SSM, Previous years rates 2002 - 2007

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

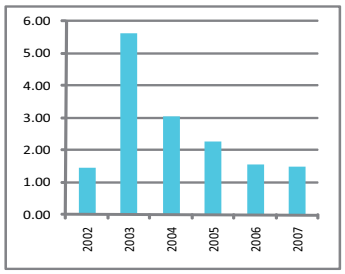
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002*	2003-2007
Total births						**13,690**	**65,053**
Anencephaly						1.46	2.77
Spina bifida						2.19	2.46
Encephalocele						2.19	1.08
Microcephaly						2.19	1.38
Holoprosencephaly						0.00	0.31
Hydrocephaly						2.19	2.00
Anophthalmos						0.00	0.15
Microphthalmos						2.19	0.46
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.00	0.31
Microtia						2.19	2.61
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						1.46	1.38
Tetralogy of Fallot						2.92	0.77
Hypoplastic left heart syndrome						0.00	0.46
Coarctation of aorta						0.00	0.00
Choanal atresia, bilateral						0.00	0.61
Cleft palate without cleft lip						5.11	4.46
Cleft lip with or without cleft palate						9.50	11.99
Oesophageal atresia / stenosis with or without fistula						1.46	1.08
Small intestine atresia / stenosis						2.19	0.77
Anorectal atresia / stenosis						1.46	2.77
Undescended testis (36 weeks of gestation or later)						4.38	8.92
Hypospadias						10.96	7.22
Epispadias						0.00	0.15
Indeterminate sex						1.46	0.46
Renal agenesis						0.00	0.92
Cystic kidney						0.00	0.92
Bladder exstrophy						0.00	0.15
Polydactyly, preaxial						10.96	6.76
‘Total Limb reduction defects (include unspecified)						2.19	4.61
Transverse						2.19	2.77
Preaxial						0.00	0.31
Postaxial						0.00	0.00
Intercalary						0.00	0.00
Mixed						0.00	0.00
Unspecified						0.00	0.77
Diaphragmatic hernia						1.46	1.08
Omphalocele						1.46	1.38
Gastroschisis						0.73	2.00
Unspecified Omphalocele / Gastroschisis						0.00	0.46
Prune belly sequence						0.73	0.15
Trisomy 13						0.73	1.38
Trisomy 18						1.46	1.08
Down syndrome, all ages (include age unknown)						18.26	23.83
<20						0.00	11.20
20-24						0.00	6.90
25-29						10.93	7.34
30-34						12.73	15.07
35-39						64.85	66.00
40-44						198.51	209.09
45+						0.00	510.20
unknown						---	---

* data include less than 5 years

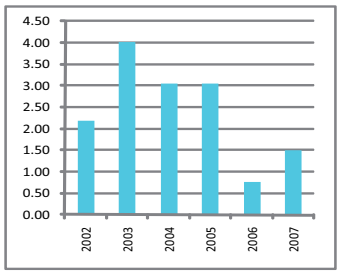
Chile, Maule: RRMC-SSM

Time trends 2002-2007 (Birth prevalence rates per 10,000)

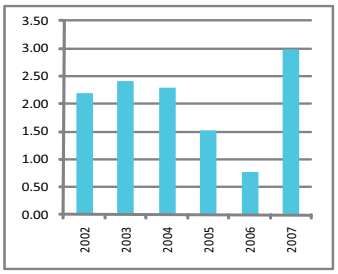
Anencephaly



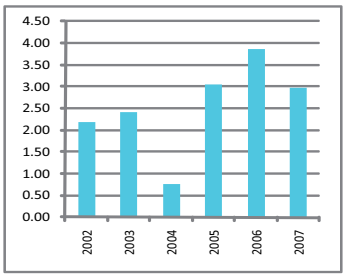
Spina Bifida



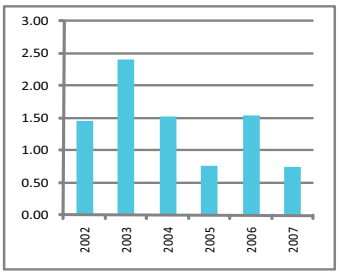
Hydrocephaly



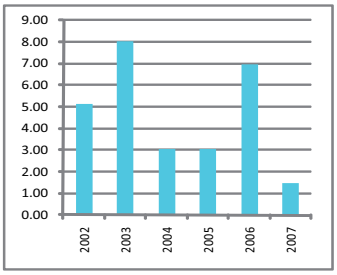
Microtia



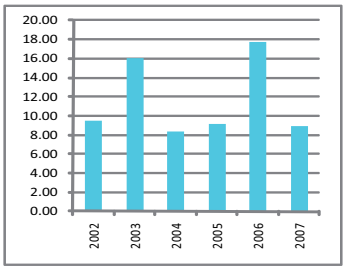
Transposition of great vessels



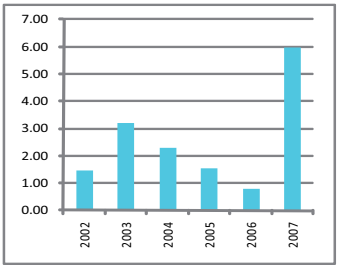
Cleft palate without cleft lip



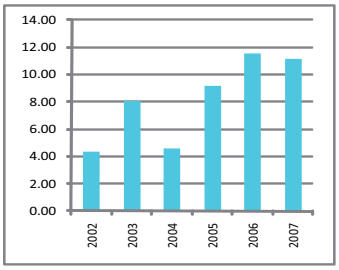
Cleft lip with or without cleft palate



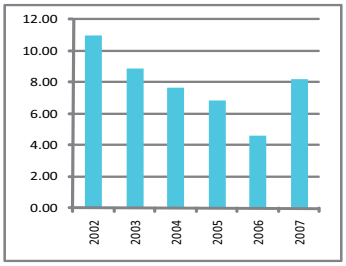
Anorectal atresia/stenosis



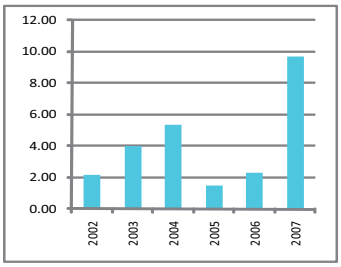
Undescended testis



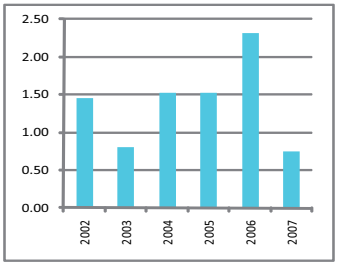
Hypospadias



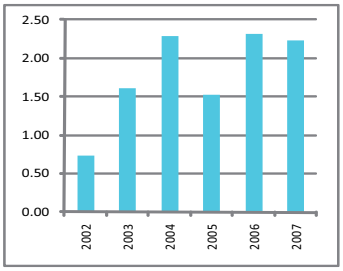
Limb reduction defects



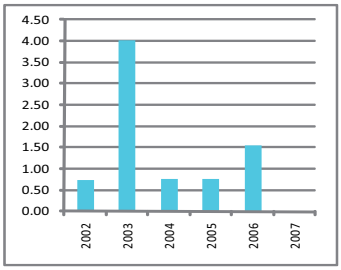
Omphalocele



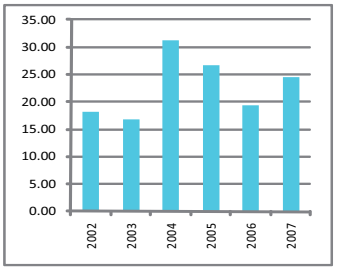
Gastroschisis



Trisomy 13

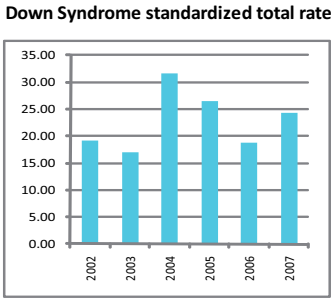


Down Syndrome



Note: L+S rates

Chile, Maule: RRMC-SSM



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.

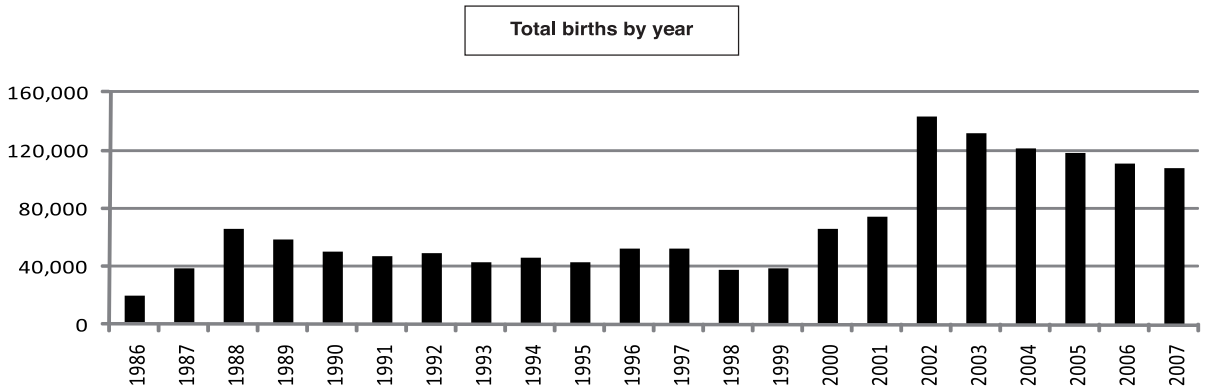
Exposure information:
The mother of each reported infant and the mother of a control infant, the next non malformed infant born at the hospital with the same sex as the proband are interviewed on various exposures, including drug usage and parental occupation.

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.

Addresses and Staff:
Maria Teresa Pérez Mateo, Recumac
Centro Nacional de Genética Medica ISCM-Habana
Victoria de Giròn, C.P. 16000
Ciudad de la Habana. Cuba.

Email: mauro@infomed.sld.cu

Cuba: RECUMAC



Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	129	98.5	Cystic kidney	80	72.1
Spina bifida	117	79.6	Limb reduction defects	25	31.3
Encephalocele	52	92.9	Diaphragmatic hernia	54	71.1
Holoprosencephaly	93	96.9	Omphalocele	54	84.4
Hydrocephaly	211	84.1	Gastroschisis	172	92.5
Hypoplastic left heart syndrome	55	82.1	Trisomy 13	37	71.2
Cleft palate without cleft lip	4	7.0	Trisomy 18	42	73.7
Cleft lip with or without cleft palate	36	21.8	Down syndrome	128	31.4
Renal agenesis	16	57.1			

Total ToPs with births defects = 2,923 (Ratio ToPs/Births: 8.69 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Cuba: RECUMAC, 2007

Live births (LB)	105,389
Stillbirths (SB)	1,968
Total births	107,357
Number of terminations of pregnancy (ToP) for birth defects	1,159

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	31	2.98
Spina bifida	2	0	70	6.71
Encephalocele	0	0	18	1.68
Microcephaly	1	0	3	0.37
Holoprosencephaly	2	0	4	0.56
Hydrocephaly	6	0	109	10.71
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.09
Unspecified Anophthalmos/Microphthalmos	1	0	0	0.09
Anotia	2	0	0	0.19
Microtia	6	0	0	0.56
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	4	0	5	0.84
Tetralogy of Fallot	10	0	12	2.05
Hypoplastic left heart syndrome	0	1	22	2.14
Coarctation of aorta	2	1	2	0.47
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	15	0	0	1.40
Cleft lip with or without cleft palate	44	0	13	5.31
Oesophageal atresia/stenosis with or without fistula	14	0	13	2.51
Small intestine atresia/stenosis	11	2	22	3.26
Anorectal atresia/stenosis	10	0	2	1.12
Undescended testis (36 weeks of gestation or later)	32	0	0	2.98
Hypospadias	100	1	0	9.41
Epispadias	1	0	0	0.09
Indeterminate sex	4	0	0	0.37
Renal agenesis	4	0	5	0.84
Cystic kidney	9	0	29	3.54
Bladder exstrophy	1	0	0	0.09
Polydactyly, preaxial	4	0	0	0.37
Total Limb reduction defects (include unspecified)	22	0	13	3.26
Transverse	7	0	3	0.93
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	3	0	2	0.47
Mixed	5	0	2	0.65
Unspecified	7	0	6	1.21
Diaphragmatic hernia	5	1	14	1.86
Omphalocele	3	0	17	1.86
Gastroschisis	4	0	72	7.08
Unspecified Omphalocele/Gastroschisis	1	0	0	0.09
Prune belly sequence	0	0	1	0.09
Trisomy 13	3	1	15	1.77
Trisomy 18	2	0	17	1.77
Down syndrome, all ages (include age unknown)	84	1	55	13.04
<20	7	0	4	nr
20-24	11	0	8	nr
25-29	11	0	4	nr
30-34	15	1	4	nr
35-39	31	0	19	nr
40-44	9	0	14	nr
45+	0	0	0	nr
unknown	0	0	2	---

nr = not reported

Cuba: RECUMAC, Previous years rates 1986 - 2007

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

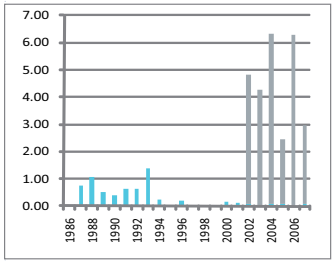
	1974-1977	1978-1982	1983-1987*	1988-1992	1993-1997	1998-2002	2003-2007
Total births			**67,317**	**269,921**	**235,318**	**360,755**	**589,469**
Anencephaly			0.74	0.67	0.34	1.97	4.48
Spina bifida			4.90	3.96	2.76	2.72	4.72
Encephalocele			0.30	0.37	0.25	0.28	1.32
Microcephaly			0.45	0.52	0.38	0.39	0.51
Holoprosencephaly			0.45	0.07	0.08	0.08	1.71
Hydrocephaly			2.23	3.41	2.17	3.99	6.85
Anophthalmos			0.00	0.07	0.00	0.08	0.12
Microphthalmos			0.00	0.07	0.04	0.19	0.17
Unspecified Anophthalmos / Microphthalmos			0.00	0.00	0.00	0.00	0.07
Anotia			0.00	0.00	0.00	0.08	0.12
Microtia			1.04	0.63	0.89	0.55	0.53
Unspecified Anotia / Microtia			0.00	0.00	0.00	0.00	0.07
Transposition of great vessels			0.45	0.37	0.81	1.25	1.75
Tetralogy of Fallot			0.00	0.30	0.42	1.55	1.49
Hypoplastic left heart syndrome			1.34	0.56	0.72	0.61	1.51
Coarctation of aorta			0.00	0.07	0.13	0.25	0.58
Choanal atresia, bilateral			0.45	0.07	0.08	0.22	0.12
Cleft palate without cleft lip			1.63	1.22	1.49	1.75	1.54
Cleft lip with or without cleft palate			4.31	4.71	6.67	5.77	4.51
Oesophageal atresia / stenosis with or without fistula			1.04	1.19	1.87	2.47	2.53
Small intestine atresia / stenosis			1.63	0.52	0.72	1.03	2.02
Anorectal atresia / stenosis			1.04	1.19	1.44	1.66	1.07
Undescended testis (36 weeks of gestation or later)			5.79	3.00	4.89	2.19	2.93
Hypospadias			14.86	14.41	11.98	8.32	9.03
Epispadias			0.30	0.30	0.13	0.14	0.12
Indeterminate sex			0.45	0.11	0.21	0.36	0.41
Renal agenesis			0.89	0.33	0.38	0.53	0.80
Cystic kidney			1.19	1.26	0.59	1.41	2.78
Bladder exstrophy			0.30	0.11	0.25	0.14	0.10
Polydactyly, preaxial			0.30	0.07	0.25	0.78	0.68
'Total Limb reduction defects (include unspecified)			2.82	2.48	2.93	2.52	2.22
Transverse			1.04	1.04	0.89	0.55	0.64
Preaxial			0.00	0.00	0.00	0.06	0.00
Postaxial			0.00	0.00	0.00	0.00	0.00
Intercalary			0.00	0.00	0.00	0.08	0.15
Mixed			0.00	0.00	0.00	0.25	0.31
Unspecified			1.78	1.44	2.04	1.58	1.12
Diaphragmatic hernia			1.19	1.37	1.66	1.75	1.82
Omphalocele			0.89	0.70	0.55	0.91	1.85
Gastroschisis			0.30	0.37	0.55	1.61	4.14
Unspecified Omphalocele / Gastroschisis			0.30	0.04	0.00	0.00	0.27
Prune belly sequence			0.15	0.15	0.00	0.00	0.08
Trisomy 13			0.30	0.59	0.34	0.67	1.24
Trisomy 18			0.30	0.07	0.47	0.33	1.29
Down syndrome, all ages (include age unknown)			9.51	7.89	6.97	8.51	11.15
<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

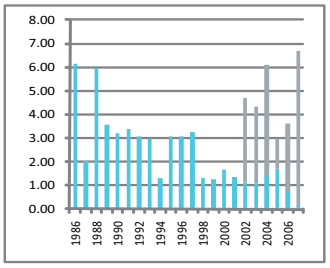
Cuba: RECUMAC

'Time trends 1985-2007 (Birth prevalence rates per 10,000)

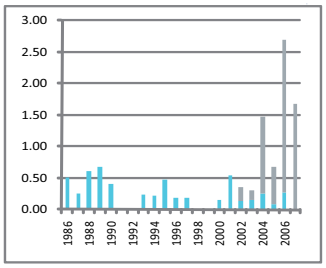
Anencephaly



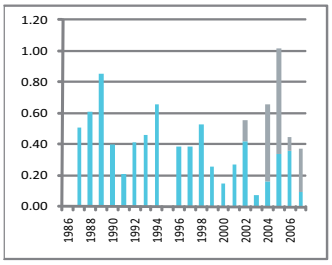
Spina Bifida



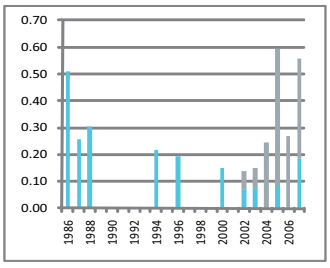
Encephalocele



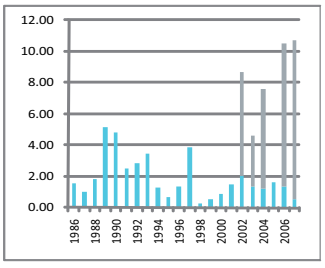
Microcephaly



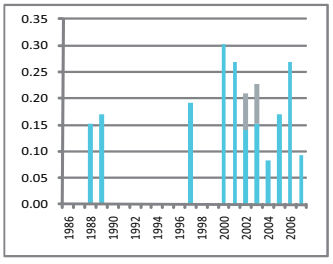
Holoprosencephaly



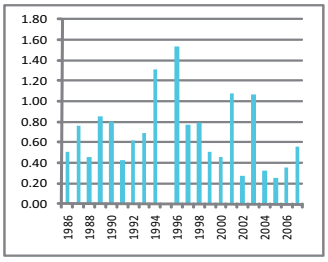
Hydrocephaly



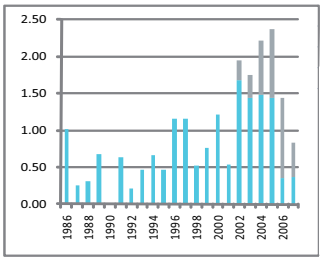
Microphthalmos



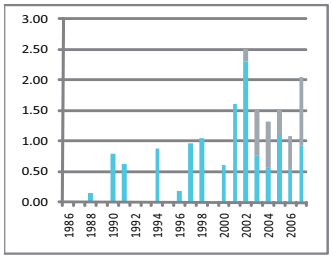
Microtia



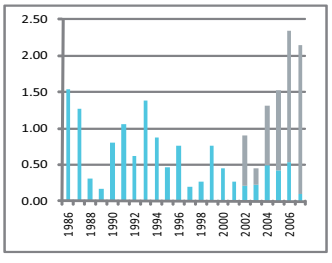
Transposition of great vessels



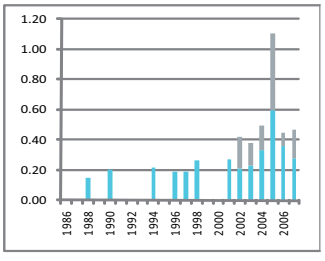
Tetralogy of Fallot



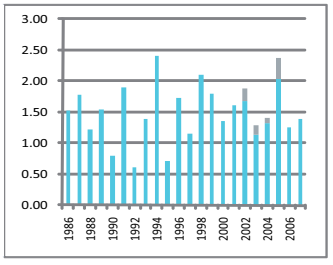
Hypoplastic left heart syndrome



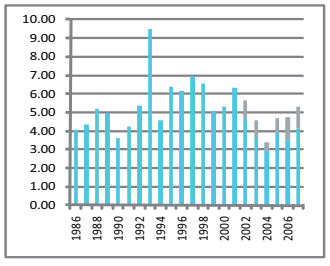
Coarctation of aorta



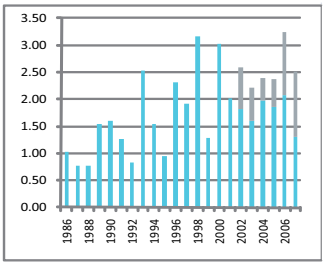
Cleft palate without cleft lip



Cleft lip with or without cleft palate



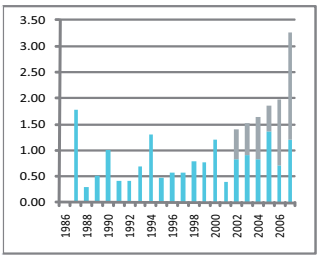
Oesophageal atresia/stenosis with or without fistula



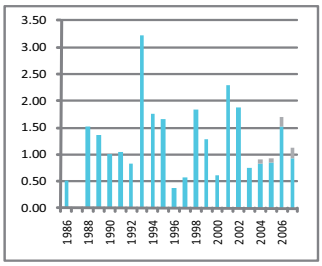
Note: L+S rates, ToP rates

Cuba: RECUMAC

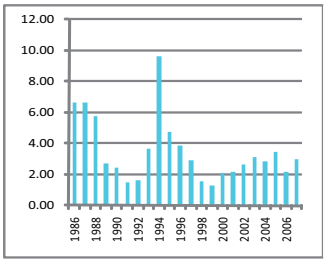
Small intestine atresia/stenosis



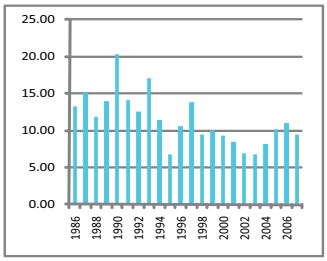
Anorectal atresia/stenosis



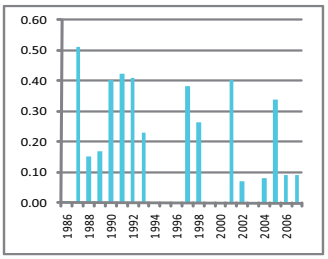
Undescended testis



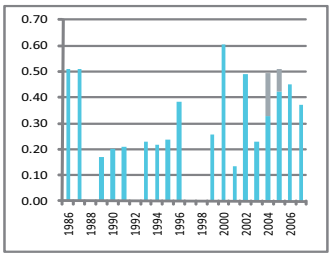
Hypospadias



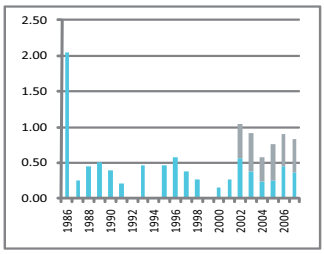
Epispadias



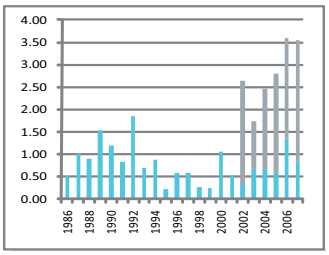
Indeterminate sex



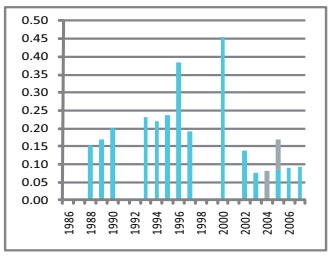
Renal agenesis



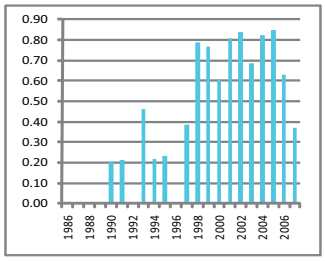
Cystic kidney



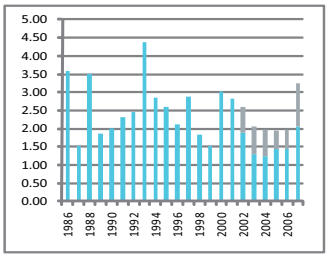
Bladder exstrophy



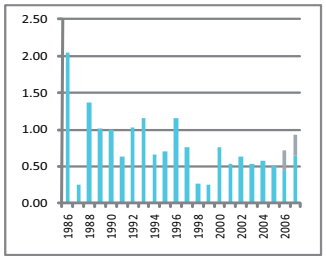
Polydactyly, preaxial



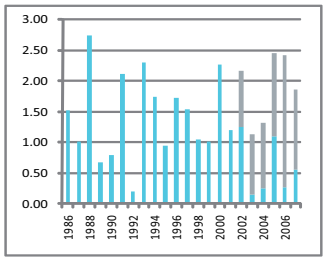
Limb reduction defects



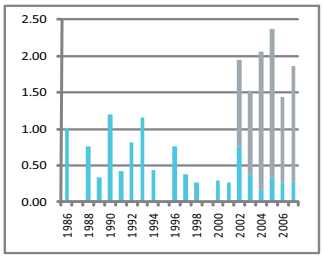
Limb reduction defects - transverse



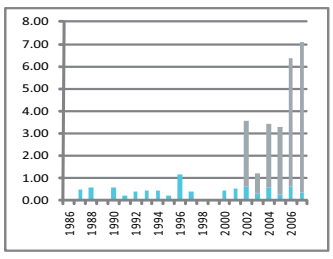
Diaphragmatic hernia



Omphalocele



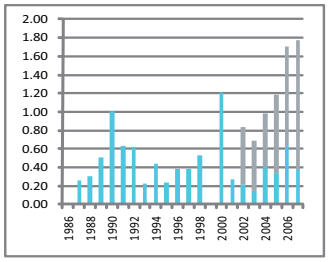
Gastroschisis



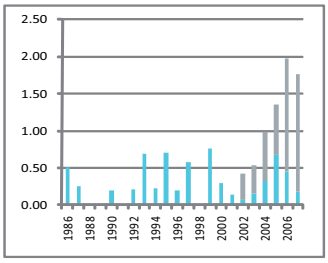
Note: L+S rates, ToP rates

Cuba: RECUMAC

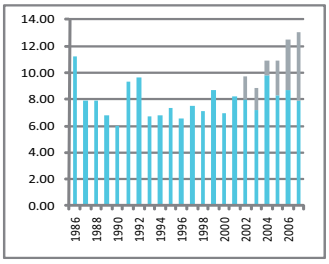
Trisomy 13



Trisomy 18



Down Syndrome



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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National Register of Congenital Anomalies in the Czech Republic
Institute of Health Information and Statistics of the Czech Republic

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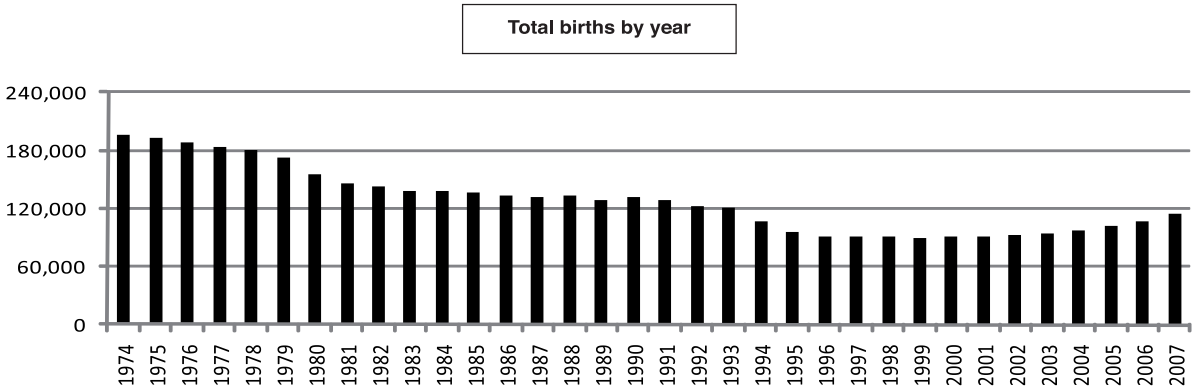
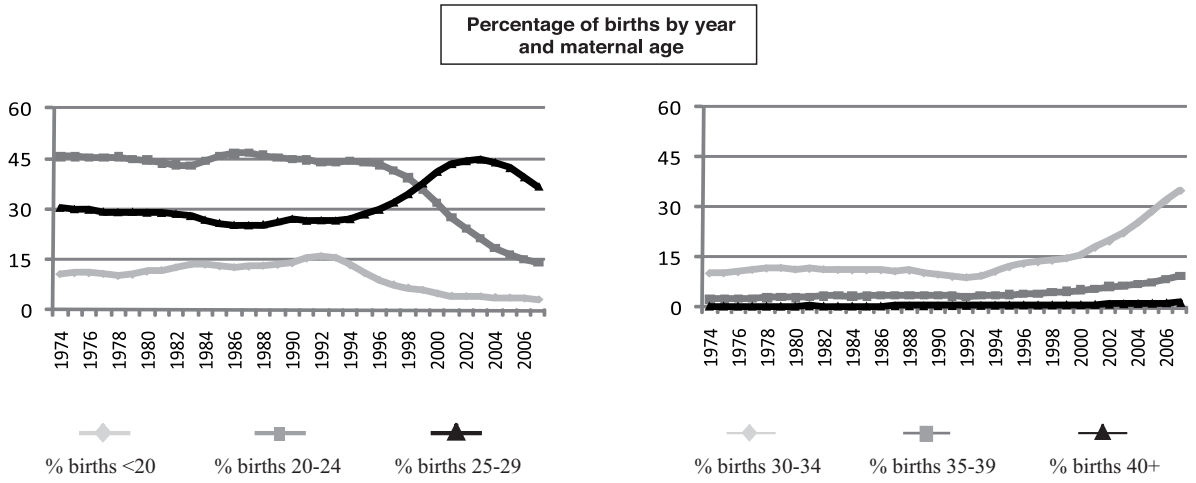
Fax: 420-26-1083636
E-mail: registrvvv@seznam.cz
Websites: www.vrozene-vady.cz
http://www.uzis.cz/

Czech Republic





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	84	93.3	Cystic kidney	33	17.2
Spina bifida	103	84.4	Limb reduction defects	25	12.1
Encephalocele	41	66.1	Diaphragmatic hernia	19	22.6
Holoprosencephaly	12	35.3	Omphalocele	52	64.2
Hydrocephaly	87	64.9	Gastroschisis	68	68.0
Hypoplastic left heart syndrome	33	51.6	Trisomy 13	49	75.4
Cleft palate without cleft lip	20	8.1	Trisomy 18	145	89.0
Cleft lip with or without cleft palate	18	5.5	Down syndrome	515	77.6
Renal agenesis	43	18.5			

Total ToPs with births defects = 2,154 (Ratio ToPs/Births: 6.66 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Czech Republic: 2007

Live births (LB)	114,052
Stillbirths (SB)	17
Total births	114,069
Number of terminations of pregnancy (ToP) for birth defects	828

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	36	3.24
Spina bifida	16	0	42	5.08
Encephalocele	4	0	23	2.37
Microcephaly	11	0	1	1.05
Holoprosencephaly	0	0	1	0.09
Hydrocephaly	21	2	37	5.26
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	7	0	0	0.61
Anotia	0	0	0	0.00
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	4	0	0	0.35
Transposition of great vessels	45	0	12	5.00
Tetralogy of Fallot	41	0	8	4.30
Hypoplastic left heart syndrome	15	1	30	4.03
Coarctation of aorta	57	0	8	5.70
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	72	1	20	8.15
Cleft lip with or without cleft palate	110	1	0	9.73
Oesophageal atresia/stenosis with or without fistula	28	0	0	2.45
Small intestine atresia/stenosis	40	0	0	3.51
Anorectal atresia/stenosis	40	0	0	3.51
Undescended testis (36 weeks of gestation or later)	0	0	0	0.00
Hypospadias	360	0	0	31.56
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	59	0	22	7.10
Cystic kidney	69	1	8	6.84
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	157	1	0	13.85
Total Limb reduction defects (include unspecified)	78	0	10	7.71
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	27	0	11	3.33
Omphalocele	16	0	22	3.33
Gastroschisis	6	0	29	3.07
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	18	1.75
Trisomy 18	7	0	41	4.21
Down syndrome, all ages (include age unknown)	58	0	196	22.27
<20	1	0	1	5.48
20-24	5	0	8	7.97
25-29	16	0	31	11.22
30-34	20	0	68	22.10
35-39	10	0	57	62.55
40-44	5	0	27	199.38
45+	0	0	4	666.67
unknown	1	0	0	---

nr = not reported

Czech Republic: Previous years rates 1974 - 2007

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

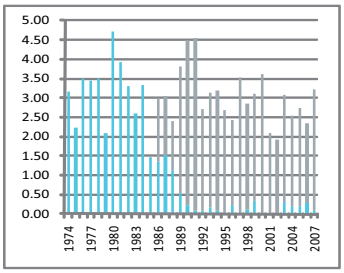
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**759,683**	**795,463**	**677,618**	**644,272**	**505,976**	**455,797**	**515,551**
Anencephaly	3.08	3.47	2.69	3.60	3.00	2.72	2.79
Spina bifida	4.07	3.86	3.66	3.97	4.03	3.86	3.98
Encephalocele	0.47	0.59	0.55	1.16	0.85	0.92	1.73
Microcephaly	1.09	1.06	0.93	0.82	0.95	1.03	1.63
Holoprosencephaly	nr	nr	nr	nr	0.17*	0.42	1.05
Hydrocephaly	2.17	2.79	2.89	4.98	4.47	4.56	4.60
Anophthalmos	nr	nr	nr	nr	nr	0.07	0.03
Microphthalmos	nr	nr	nr	nr	nr	0.29	0.30
Unspecified Anophthalmos / Microphthalmos	nr	nr	nr	nr	nr	0.00	0.17
Anotia	nr	nr	nr	nr	nr	0.94	0.34
Microtia	nr	nr	nr	nr	nr	0.37	0.47
Unspecified Anotia / Microtia	nr	nr	nr	nr	nr	5.59	0.17
Transposition of great vessels	2.96	2.20	1.86	1.29	2.46*	3.91	4.19
Tetralogy of Fallot	nr	nr	nr	nr	2.49*	3.31	3.70
Hypoplastic left heart syndrome	0.63	0.53	0.72	0.66*	1.97*	2.57	2.58
Coarctation of aorta	nr	nr	nr	nr	3.55*	4.39	5.18
Choanal atresia, bilateral	nr	nr	nr	nr	0.38*	0.20	0.26*
Cleft palate without cleft lip	5.59	6.27	6.42	5.22	6.44	7.00	7.47
Cleft lip with or without cleft palate	9.44	10.42	10.65	10.26	10.10	10.79	10.51
Oesophageal atresia / stenosis with or without fistula	1.22	1.09	1.28	1.04	2.06	2.94	2.75
Small intestine atresia / stenosis	nr	nr	nr	nr	1.94*	2.54	3.53
Anorectal atresia / stenosis	1.45	1.19	0.99	0.93	2.57	3.31	3.78
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	6.52*	18.08	26.56*
Hypospadias	18.67	18.87	21.50	23.08	24.65	28.74	32.31
Epispadias	nr	nr	nr	nr	0.44*	0.39	0.43*
Indeterminate sex	nr	nr	nr	nr	0.36*	0.53	0.33*
Renal agenesis	1.66	1.51	1.27	1.72	2.21	4.04	7.49
Cystic kidney	2.29	2.78	2.45	2.75	2.96	5.07	6.13
Bladder exstrophy	0.21	0.10	0.04	0.02*	0.14*	0.20	0.16*
Polydactyly, preaxial	nr	nr	nr	12.08	13.89	12.40	14.70
‘Total Limb reduction defects (include unspecified)	4.09	4.71	5.11	5.29	5.20	5.44	6.38
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	2.54	2.55	2.52	1.74	2.15	2.57	2.83
Omphalocele	2.24	2.24	2.44	2.36	2.33	2.44	2.68
Gastroschisis	0.92	1.27	1.42	0.71	1.94	3.01	3.05
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.02	0.00
Prune belly sequence	nr	nr	nr	nr	nr	nr	0.13*
Trisomy 13	nr	nr	nr	0.26*	0.75	1.12	2.17
Trisomy 18	nr	nr	0.41*	0.78	2.17	3.62	4.85
Down syndrome, all ages (include age unknown)	8.35	8.51	8.19	8.91	12.49	16.10	19.71
<20	5.78	3.77	5.44	3.95	5.23	7.64	7.05
20-24	5.73	4.90	4.66	3.10	6.60	8.99	8.48
25-29	8.73	7.52	8.06	5.65	8.80	10.62	10.47
30-34	13.37	9.41	8.27	8.97	15.30	20.89	19.27
35-39	31.75	31.18	28.48	33.60	52.31	57.02	67.33
40-44	107.00	139.99	62.21	93.59	256.48	202.65	201.92
45+	182.93	400.00	0.00	842.11	597.02	642.86	526.32
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

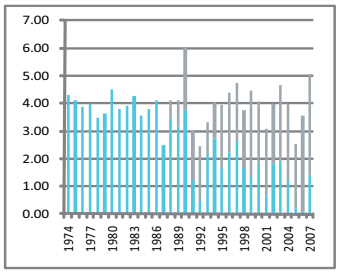
Czech Republic

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

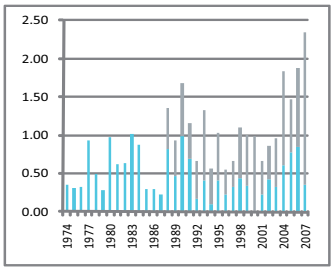
Anencephaly



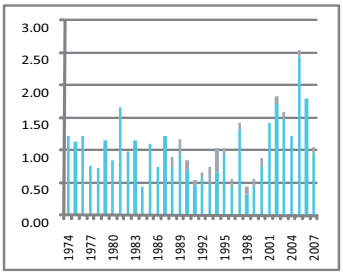
Spina Bifida



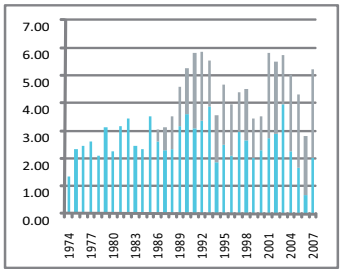
Encephalocele



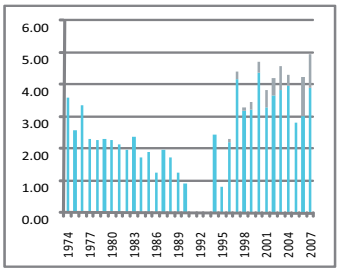
Microcephaly



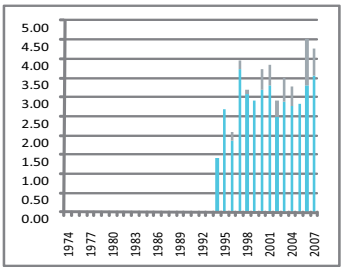
Hydrocephaly



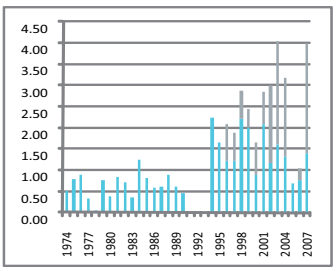
Transposition of great vessels



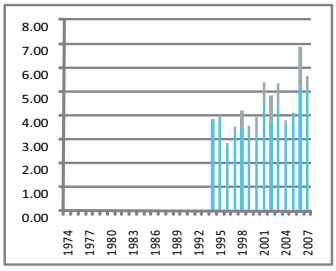
Tetralogy of Fallot



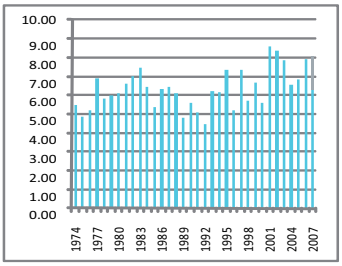
Hypoplastic left heart syndrome



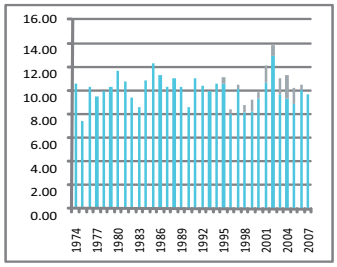
Coarctation of aorta



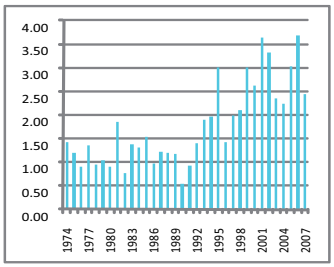
Cleft palate without cleft lip



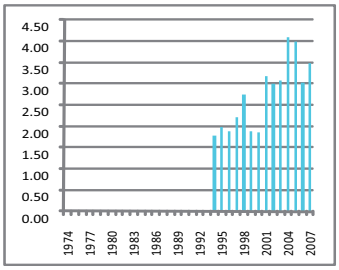
Cleft lip with or without cleft palate



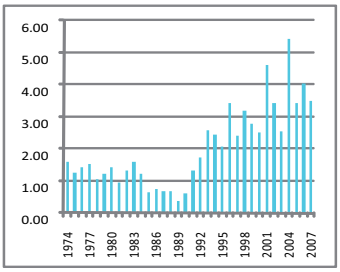
Oesophageal atresia/stenosis with or without fistula



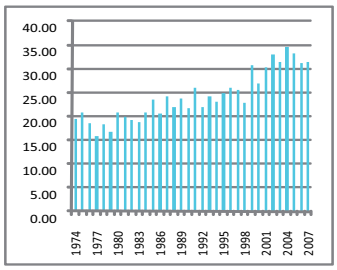
Small intestine atresia/stenosis



Anorectal atresia/stenosis



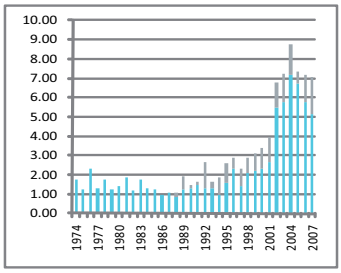
Hypospadias



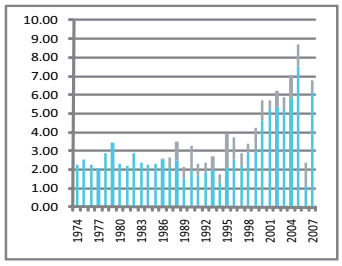
Note: L+S rates, ToP rates

Czech Republic

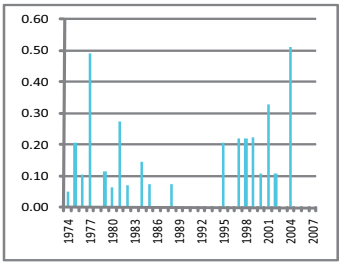
Renal agenesis



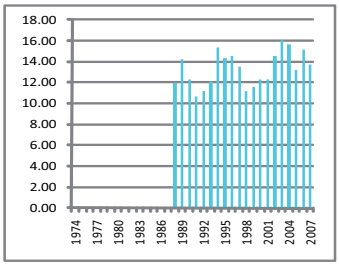
Cystic kidney



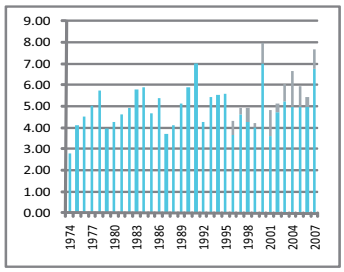
Bladder exstrophy



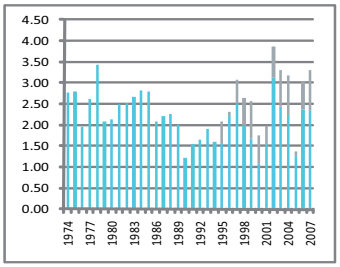
Polydactyly, preaxial



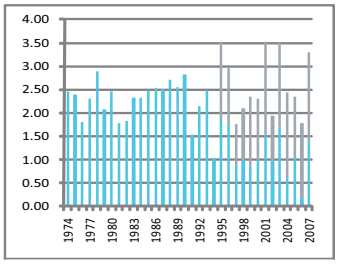
Limb reduction defects



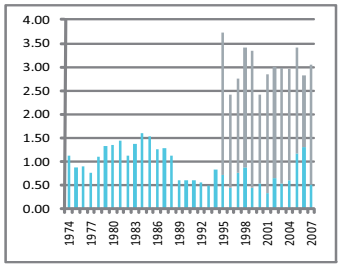
Diaphragmatic hernia



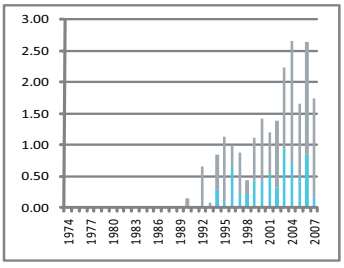
Omphalocele



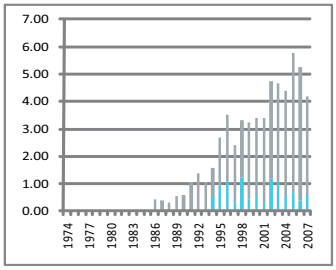
Gastroschisis



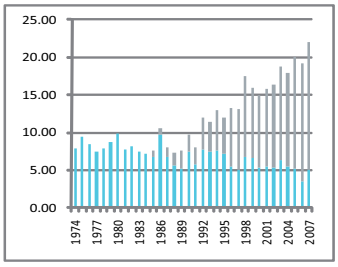
Trisomy 13



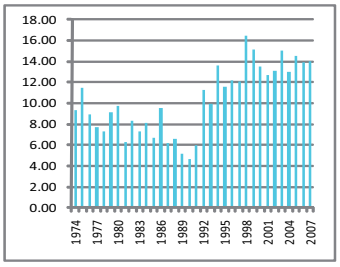
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Finland

The Finnish Register of Congenital Malformations

History:
The registry was established in 1963 and regular monitoring started in 1977. It was a founding member of the ICBDSR and is a full member. In 1998 the registry became an associate member of EUROCAT. The registry system (data collection etc.) has been changed twice, in 1985 and in 1993.

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. Selective terminations of pregnancy and spontaneous abortions with malformations have been included since 1993.

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 Welfare and Health (under the Ministry of Social Affairs and Health).

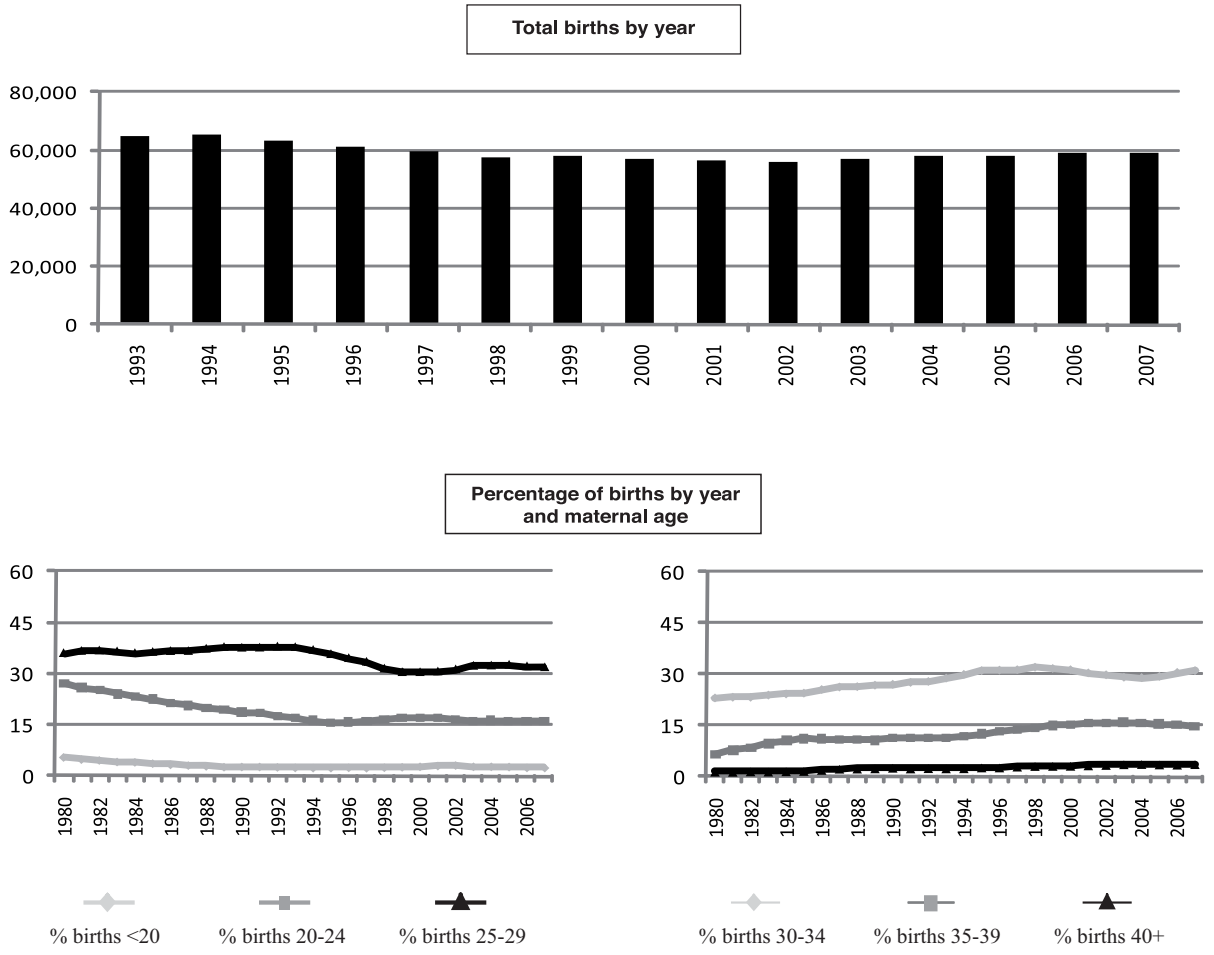
Sources and ascertainment:
Reports are obtained from delivery units, neonatal, paediatric and pathology departments, death certificates and cytogenetic laboratories. Case information is also received from the national Medical Birth Register, Abortion Register and Hospital Discharge Register. The diagnoses of the malformation cases received from 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.

Addresses and Staff:
Annukka Ritvanen, Program Director
The Finnish Register of Congenital Malformations
THL, National Institute for Welfare and Health
Lintulahdenkuja 4, P.O. Box 30, FIN-00531 Helsinki, Finland
Phone: 358-20-610 7376
Fax: 358-20-610 7459
E-mail: annukka.ritvanen(at)stakes.fi
Website: http://www.thl.fi/

Finland



Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	50	94.3	Cystic kidney	43	27.4
Spina bifida	48	60.0	Limb reduction defects	32	26.2
Encephalocele	23	71.9	Diaphragmatic hernia	24	36.4
Holoprosencephaly	28	71.8	Omphalocele	64	68.1
Hydrocephaly	34	39.1	Gastroschisis	25	39.1
Hypoplastic left heart syndrome	24	39.3	Trisomy 13	33	70.2
Cleft palate without cleft lip	21	8.6	Trisomy 18	92	75.4
Cleft lip with or without cleft palate	39	19.3	Down syndrome	275	53.4
Renal agenesis	14	66.7			

Total ToPs with births defects = 931 (Ratio ToPs/Births: 5.29 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Finland: 2007

Live births (LB)	58,729
Stillbirths (SB)	204
Total births	58,933
Number of terminations of pregnancy (ToP) for birth defects	315

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	17	3.22
Spina bifida	9	0	16	4.24
Encephalocele	4	0	11	2.55
Microcephaly	9	0	1	1.70
Holoprosencephaly	2	0	17	3.22
Hydrocephaly	16	0	13	4.92
Anophthalmos	3	0	1	0.68
Microphthalmos	1	0	1	0.34
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	16	0	3	3.22
Transposition of great vessels	14	1	1	2.71
Tetralogy of Fallot	25	1	1	4.58
Hypoplastic left heart syndrome	10	0	6	2.71
Coarctation of aorta	54	1	1	9.50
Choanal atresia, bilateral	4	0	0	0.68
Cleft palate without cleft lip	63	0	8	12.05
Cleft lip with or without cleft palate	56	0	14	11.88
Oesophageal atresia/stenosis with or without fistula	17	1	2	3.39
Small intestine atresia/stenosis	9	0	0	1.53
Anorectal atresia/stenosis	19	1	5	4.24
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	19	0	1	3.39
Epispadias	1	0	0	0.17
Indeterminate sex	3	0	1	0.68
Renal agenesis	1	0	2	0.51
Cystic kidney	36	2	17	9.33
Bladder exstrophy	5	0	0	0.85
Polydactyly, preaxial	24	0	2	4.41
Total Limb reduction defects (include unspecified)	37	0	11	8.14
Transverse	18	0	6	4.07
Preaxial	9	0	3	2.04
Postaxial	6	0	0	1.02
Intercalary	1	0	1	0.34
Mixed	2	0	0	0.34
Unspecified	1	0	1	0.34
Diaphragmatic hernia	15	0	9	4.07
Omphalocele	4	0	18	3.73
Gastroschisis	14	0	8	3.73
Unspecified Omphalocele/Gastroschisis	1	0	3	0.68
Prune belly sequence	1	0	0	0.17
Trisomy 13	3	0	20	3.90
Trisomy 18	4	2	33	6.62
Down syndrome, all ages (include age unknown)	76	7	96	30.37
<20	0	0	0	0.00
20-24	6	0	3	9.48
25-29	13	2	10	13.35
30-34	19	3	18	21.90
35-39	25	0	37	70.74
40-44	12	2	27	194.77
45+	1	0	1	198.02
unknown	0	0	0	---

nr = not reported

Finland: Previous years rates 1993 - 2007

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

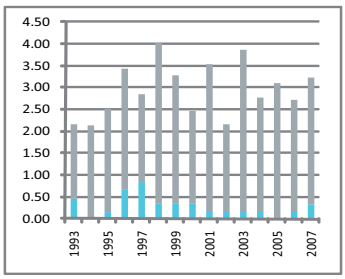
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births					**314,480**	**284,261**	**290,646**
Anencephaly					2.61	3.10	3.13
Spina bifida					4.39	4.64	4.54
Encephalocele					1.34	1.79	1.72
Microcephaly					2.32	2.15	2.06
Holoprosencephaly					1.37	1.30	2.00
Hydrocephaly					7.47	6.40	4.71
Anophthalmos					0.41	0.67	0.52
Microphthalmos					1.69	1.79	0.93
Unspecified Anophthalmos / Microphthalmos					nr	nr	nr
Anotia					nr	nr	nr
Microtia					nr	nr	nr
Unspecified Anotia / Microtia					4.80	4.36	4.47
Transposition of great vessels					4.13	4.22	3.44
Tetralogy of Fallot					2.93	3.83	4.23
Hypoplastic left heart syndrome					2.89	4.68	3.68
Coarctation of aorta					8.84	10.62	9.36
Choanal atresia, bilateral					0.92	0.88	0.89
Cleft palate without cleft lip					14.88	13.61	14.00
Cleft lip with or without cleft palate					11.38	10.80	11.04
Oesophageal atresia / stenosis with or without fistula					3.37	4.12	3.82
Small intestine atresia / stenosis					1.21	0.99	1.31
Anorectal atresia / stenosis					5.31	5.00	5.75
Undescended testis (36 weeks of gestation or later)					nr	nr	nr
Hypospadias					3.37	3.27	3.65
Epispadias					0.25	0.28	0.41
Indeterminate sex					0.89	1.72	1.62
Renal agenesis					1.91	1.44	1.34
Cystic kidney					6.36	7.00	8.46
Bladder exstrophy					0.51	0.63	0.76
Polydactyly, preaxial					4.71	4.19	4.54
‘Total Limb reduction defects (include unspecified)					7.28	7.14	7.43
Transverse					4.36	3.24	4.16
Preaxial					1.75	2.50	1.65
Postaxial					0.32	0.46	0.55
Intercalary					0.38	0.35	0.45
Mixed					0.41	0.25	0.34
Unspecified					0.03	0.07	0.17
Diaphragmatic hernia					2.35	2.99	3.30
Omphalocele					3.75	4.50	5.57
Gastroschisis					1.88	3.10	3.54
Unspecified Omphalocele / Gastroschisis					0.19	0.35	0.41
Prune belly sequence					0.35	0.21	0.21
Trisomy 13					2.32	1.86	2.51
Trisomy 18					5.34	6.54	6.78
Down syndrome, all ages (include age unknown)					23.02	23.96	28.35
<20					13.97	6.09	11.41
20-24					6.50	7.12	9.35
25-29					11.41	9.37	12.62
30-34					18.10	17.36	18.71
35-39					56.66	54.72	58.46
40-44					172.80	173.63	202.81
45+					327.51	295.86	410.96
unknown					---	---	---

nr = not reported

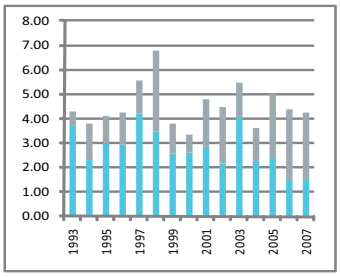
Finland

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

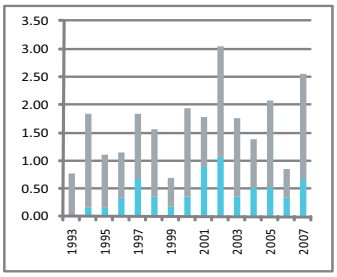
Anencephaly



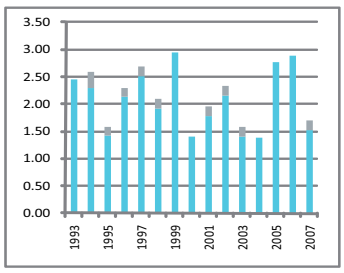
Spina Bifida



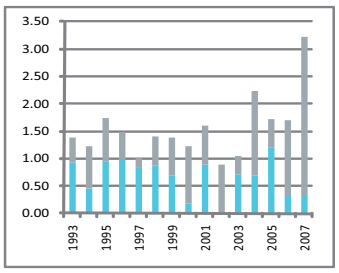
Encephalocele



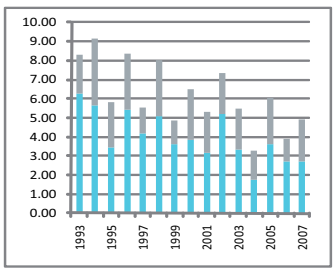
Microcephaly



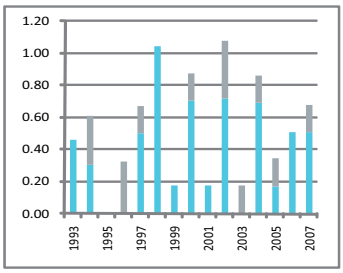
Holoprosencephaly



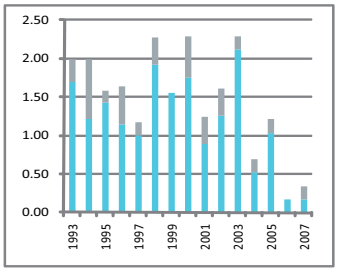
Hydrocephaly



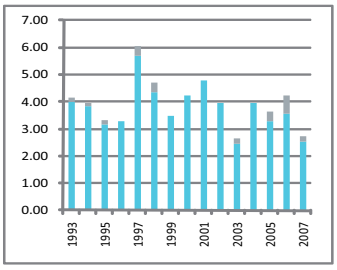
Anophthalmos



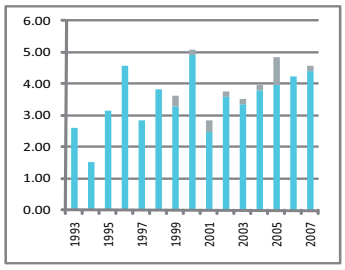
Microphthalmos



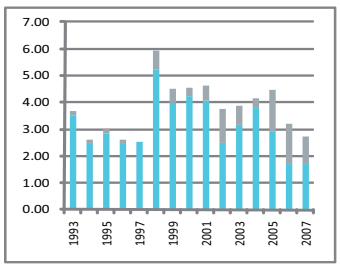
Transposition of great vessels



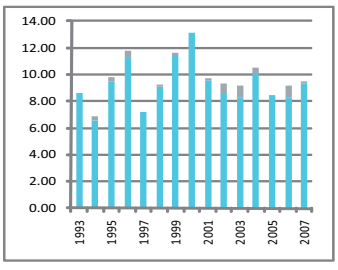
Tetralogy of Fallot



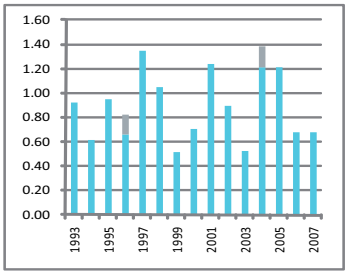
Hypoplastic left heart syndrome



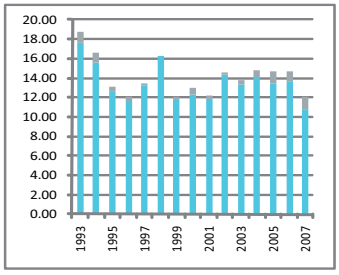
Coarctation of aorta



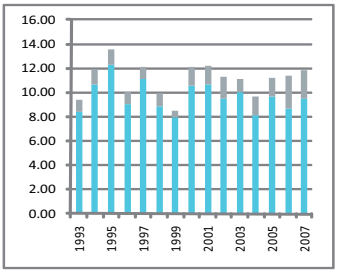
Choanal atresia. bilateral



Cleft palate without cleft lip



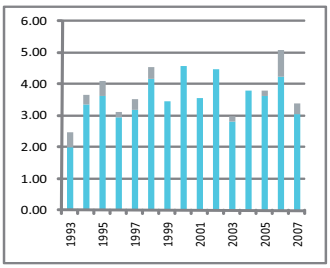
Cleft lip with or without cleft palate



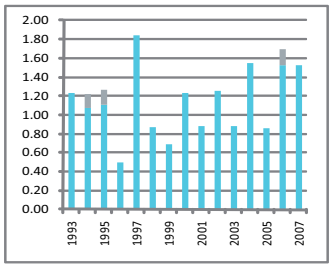
Note: L+S rates, ToP rates

Finland

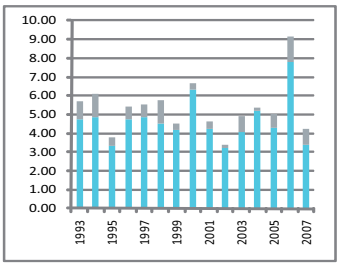
Oesophageal atresia/stenosis with or without fistula



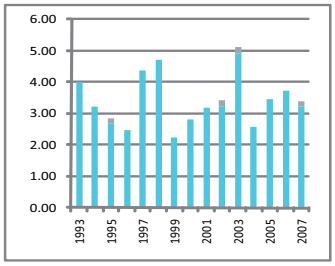
Small intestine atresia/stenosis



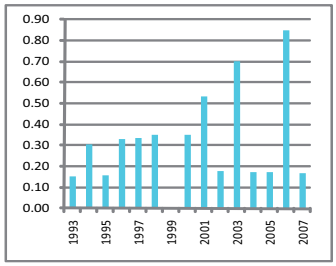
Anorectal atresia/stenosis



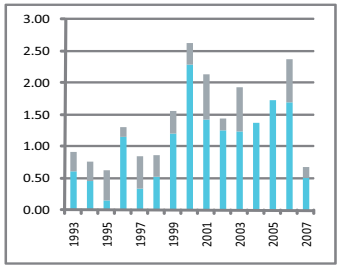
Hypospadias



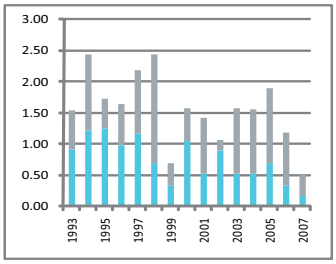
Epispadias



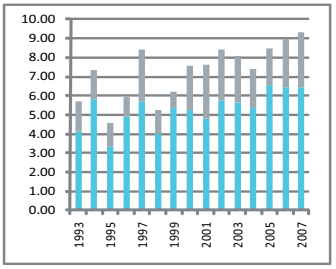
Indeterminate sex



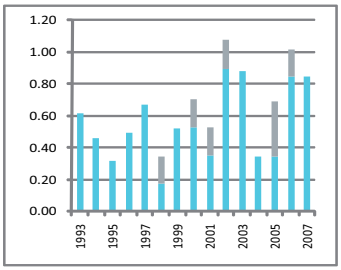
Renal agenesis



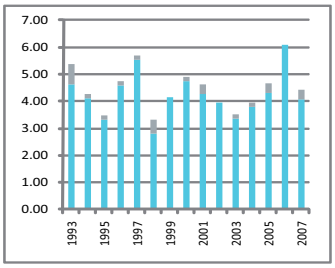
Cystic kidney



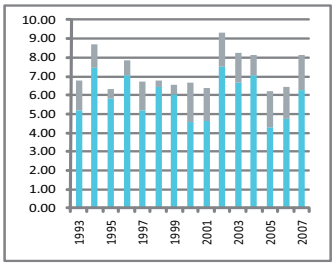
Bladder exstrophy



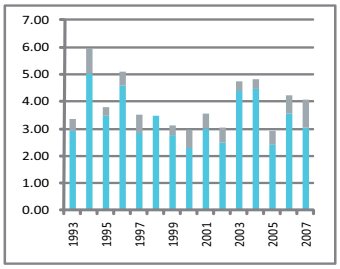
Polydactyly, preaxial



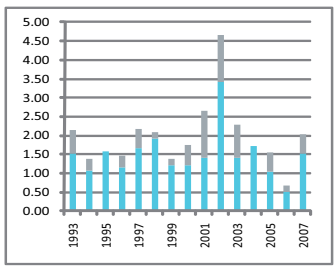
Limb reduction defects



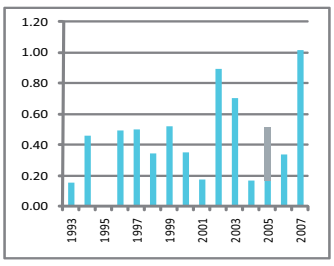
Limb reduction defects - transverse



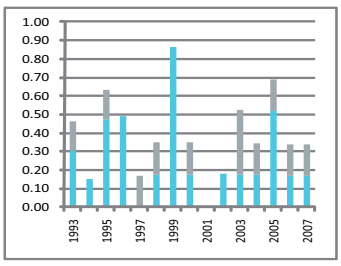
Polydactyly, preaxial



Limb reduction defects



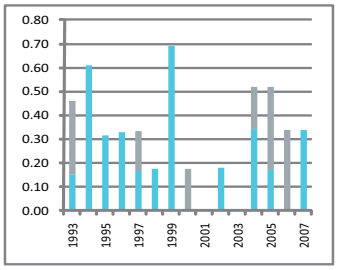
Limb reduction defects - transverse



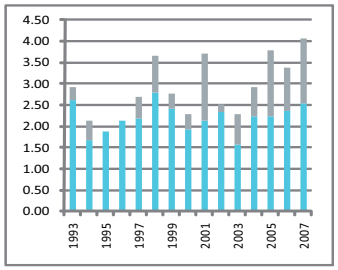
Note: L+S rates, ToP rates

Finland

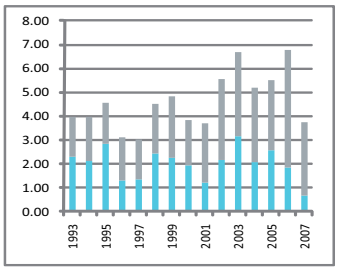
Limb reduction defects - mixed



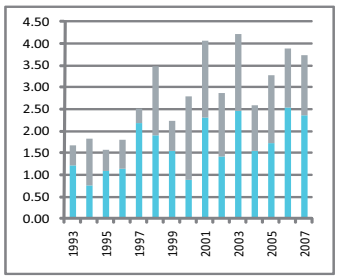
Diaphragmatic hernia



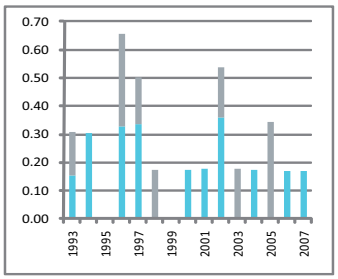
Omphalocele



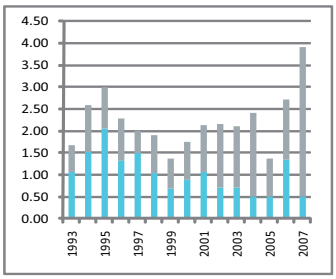
Gastroschisis



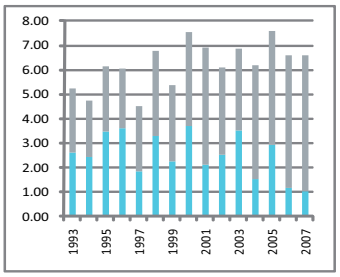
Prune belly sequence



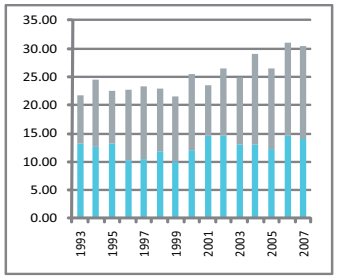
Trisomy 13



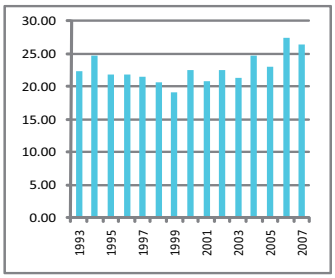
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

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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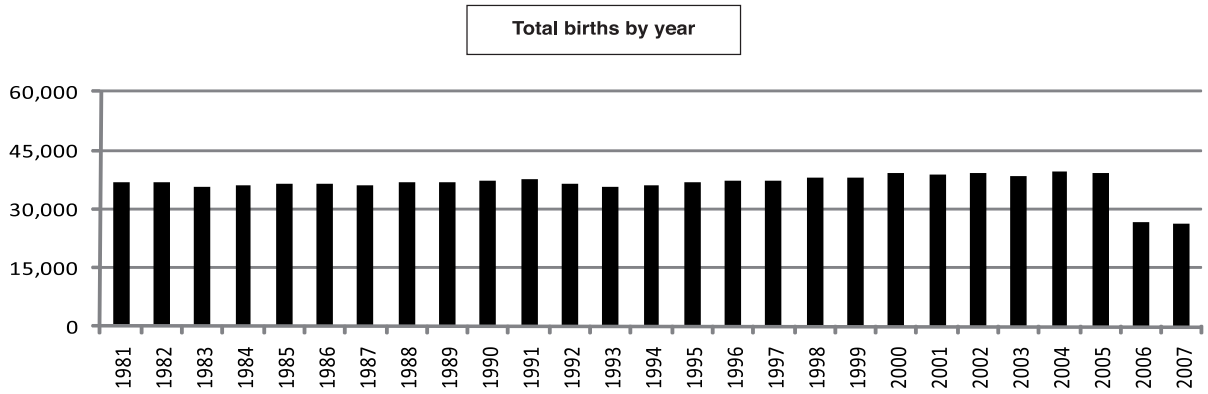
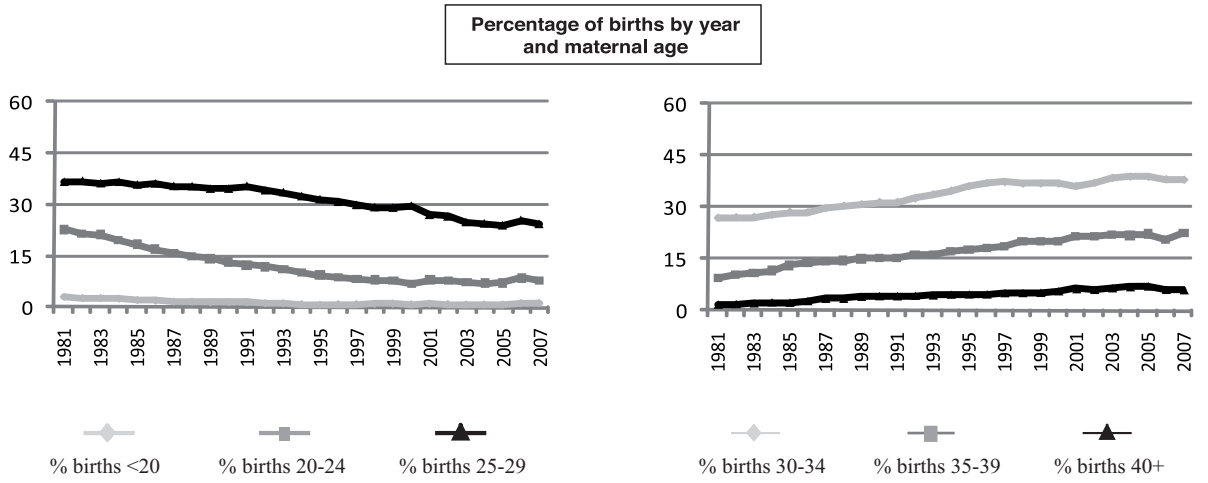
Phone: 33-1-42345575
E-mail: babak.khoshnood@inserm.fr

Nathalie Lelong
E-mail: Nathalie.lelong@inserm.fr

France: Paris





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	42	95.5	Cystic kidney	24	26.7
Spina bifida	30	73.2	Limb reduction defects	33	62.3
Encephalocele	19	70.4	Diaphragmatic hernia	8	21.1
Holoprosencephaly	23	92.0	Omphalocele	35	66.0
Hydrocephaly	61	41.8	Gastroschisis	1	7.7
Hypoplastic left heart syndrome	21	58.3	Trisomy 13	37	88.1
Cleft palate without cleft lip	11	17.5	Trisomy 18	116	90.6
Cleft lip with or without cleft palate	21	24.7	Down syndrome	344	81.5
Renal agenesis	22	71.0			

Total ToPs with births defects = 1,068 (Ratio ToPs/Births: 11.6 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Paris, 2007

Live births (LB)	26,059
Stillbirths (SB)	280
Total births	26,339
Number of terminations of pregnancy (ToP) for birth defects	283

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	9	3.42
Spina bifida	2	0	14	6.07
Encephalocele	5	0	8	4.94
Microcephaly	2	1	1	1.52
Holoprosencephaly	1	0	7	3.04
Hydrocephaly	30	0	14	16.71
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	1	0.76
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	1	1.14
Microtia	1	0	0	0.38
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	1	0	2.66
Tetralogy of Fallot	8	1	6	5.69
Hypoplastic left heart syndrome	5	0	6	4.18
Coarctation of aorta	9	1	2	4.56
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	18	1	4	8.73
Cleft lip with or without cleft palate	17	1	5	8.73
Oesophageal atresia/stenosis with or without fistula	2	0	3	1.90
Small intestine atresia/stenosis	3	0	1	1.52
Anorectal atresia/stenosis	6	0	5	4.18
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	40	0	1	15.57
Epispadias	4	0	0	1.52
Indeterminate sex	3	0	1	1.52
Renal agenesis	0	0	6	2.28
Cystic kidney	19	0	7	9.87
Bladder exstrophy	2	0	1	1.14
Polydactyly, preaxial	3	0	0	1.14
Total Limb reduction defects (include unspecified)	8	1	10	7.21
Transverse	6	1	5	4.56
Preaxial	1	0	4	1.90
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.38
Mixed	0	0	1	0.38
Unspecified	0	0	0	0.00
Diaphragmatic hernia	5	0	2	2.66
Omphalocele	6	0	13	7.21
Gastroschisis	1	0	0	0.38
Unspecified Omphalocele/Gastroschisis	0	0	3	1.14
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	15	6.07
Trisomy 18	2	3	39	16.71
Down syndrome, all ages (include age unknown)	22	1	93	20.36
<20	0	0	0	9.36
20-24	1	0	1	8.41
25-29	2	1	8	16.65
30-34	5	0	14	18.45
35-39	7	0	29	52.04
40-44	5	0	40	164.52
45+	2	0	0	338.35
unknown	0	0	1	---

nr = not reported

France: Paris, Previous years rates 1981 - 2007

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

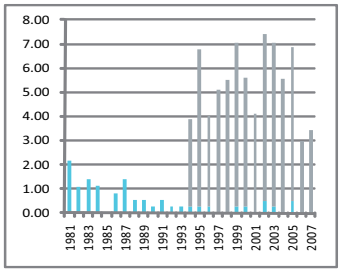
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births		**73,658**	**180,685**	**184,850**	**183,130**	**193,678**	**170,236**
Anencephaly		1.63	0.94	0.43	4.04	5.94	5.46
Spina bifida		4.07	2.44	1.19	4.37	5.32	4.58
Encephalocele		0.54	0.66	0.70	1.97	2.07	2.47
Microcephaly		2.44	2.21	1.95	3.49	2.63	3.05
Holoprosencephaly		0.00	0.44	0.32	2.24	2.79	3.47
Hydrocephaly		4.34	3.21	3.19	11.90	12.08	15.33
Anophthalmos		0.14	0.22	0.38	0.27	0.26	0.23
Microphthalmos		0.14	1.16	1.03	1.86	1.60	0.76
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.14	0.39	0.32	0.76	0.77	1.06
Microtia		0.27	0.55	0.54	0.49	0.83	0.65
Unspecified Anotia / Microtia		0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels		1.63	2.55	2.54	5.02	6.04	4.11
Tetralogy of Fallot		0.68	1.05	2.27	2.35	4.39	4.29
Hypoplastic left heart syndrome		2.04	1.49	1.19	3.49	3.41	4.29
Coarctation of aorta		0.95	1.55	2.38	3.06	4.03	3.05
Choanal atresia, bilateral		0.68	0.50	0.65	0.55	0.41	0.35
Cleft palate without cleft lip		3.94	3.98	5.19	6.50	7.07	5.87
Cleft lip with or without cleft palate		6.38	6.53	9.30	9.28	8.21	8.87
Oesophageal atresia / stenosis with or without fistula		2.17	2.49	3.41	3.82	3.98	3.70
Small intestine atresia / stenosis		0.27	0.61	1.35	2.51	2.32	4.23
Anorectal atresia / stenosis		2.72	2.88	2.43	3.55	3.61	3.58
Undescended testis (36 weeks of gestation or later)		6.79	11.24	12.17	9.56	5.94	nr
Hypospadias		9.91	10.52	13.15	12.67	12.44	15.86
Epispadias		0.00	0.39	0.54	0.38	0.36	0.70
Indeterminate sex		1.76	1.11	1.35	1.20	1.55	1.35
Renal agenesis		0.81	1.33	0.54	2.95	2.79	2.88
Cystic kidney		0.68	2.77	3.62	8.79	9.96	10.10
Bladder exstrophy		0.41	0.33	0.16	0.82	0.46	0.65
Polydactyly, preaxial		0.27	0.77	1.41	2.29	1.70	1.64
'Total Limb reduction defects (include unspecified)		nr	nr	nr	5.92*	8.05	7.11
Transverse		nr	nr	nr	1.70*	4.75	3.82
Preaxial		nr	nr	nr	0.35*	1.39	1.47
Postaxial		nr	nr	nr	0.44*	0.52	0.70
Intercalary		nr	nr	nr	0.35*	0.57	0.35
Mixed		nr	nr	nr	0.08*	0.67	0.53
Unspecified		nr	nr	nr	0.00*	0.15	0.23
Diaphragmatic hernia		1.49	2.77	3.14	4.81	5.47	4.64
Omphalocele		1.09	2.05	1.62	3.88	6.14	5.87
Gastroschisis		0.27	0.72	1.62	2.35	3.46	2.11
Unspecified Omphalocele / Gastroschisis		0.14	0.55	0.16	0.76	1.08	1.06
Prune belly sequence		0.00	0.22	0.00	0.11	0.10	0.23
Trisomy 13		0.41	0.50	0.60	2.51	4.18	4.64
Trisomy 18		1.22	1.27	1.24	5.84	10.84	14.10
Down syndrome, all ages (include age unknown)		10.18	12.23	11.85	31.84	36.45	43.47
<20		4.76	15.39	11.37	6.15	10.99	13.18
20-24		6.76	6.63	7.30	13.87	8.72	12.58
25-29		6.30	6.78	6.54	12.46	13.54	17.47
30-34		8.61	12.75	12.63	18.60	22.45	23.89
35-39		21.94	26.79	23.09	56.24	57.50	66.36
40-44		50.89	34.87	19.75	199.32	195.11	203.11
45+		405.41	118.58	92.59	402.84	272.90	389.26
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

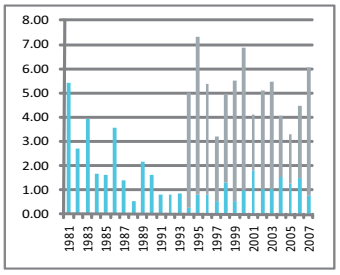
France: Paris

'Time trends 1981-2006 (Birth prevalence rates per 10,000)

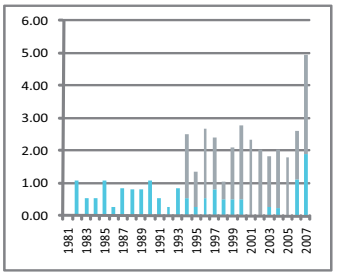
Anencephaly



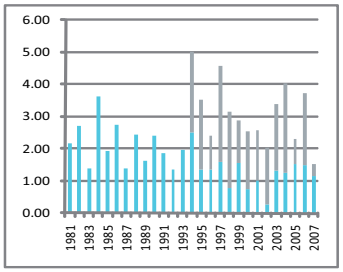
Spina Bifida



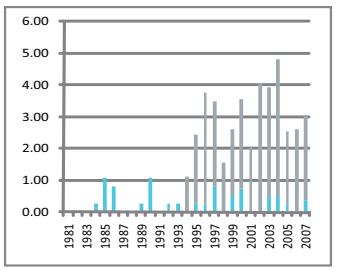
Encephalocele



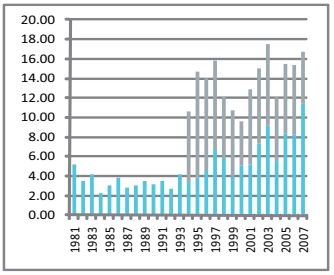
Microcephaly



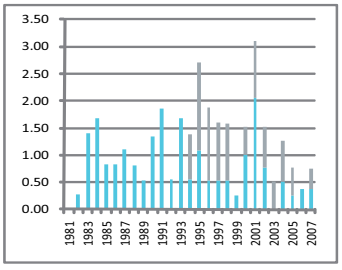
Holoprosencephaly



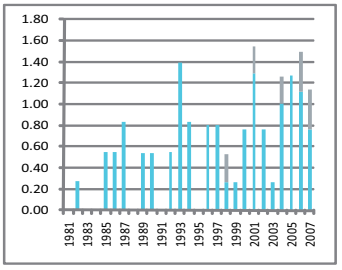
Hydrocephaly



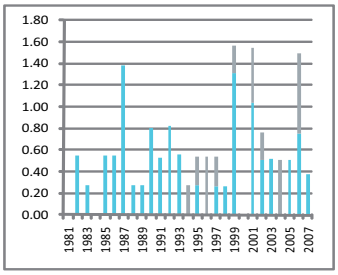
Microphthalmos



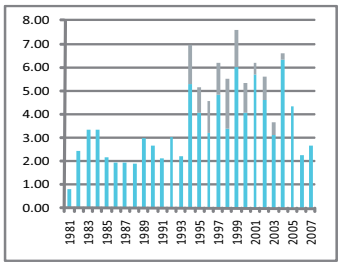
Anotia



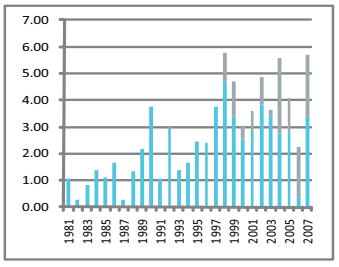
Microtia



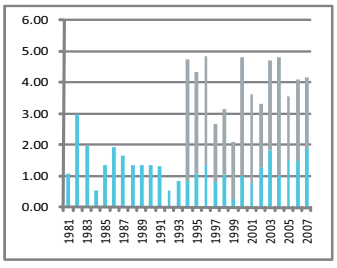
Transposition of great vessels



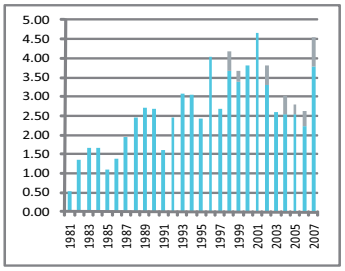
Tetralogy of Fallot



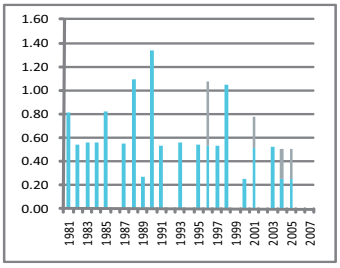
Hypoplastic left heart syndrome



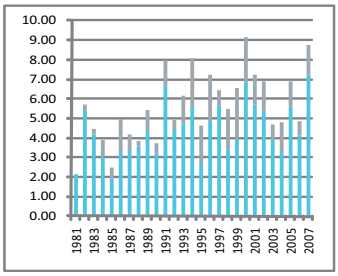
Coarctation of aorta



Choanal atresia. bilateral



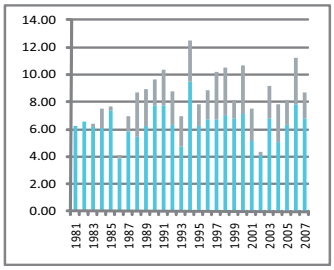
Cleft palate without cleft lip



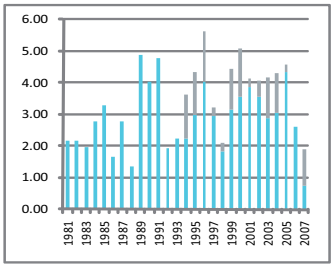
Note: L+S rates, ToP rates

France: Paris

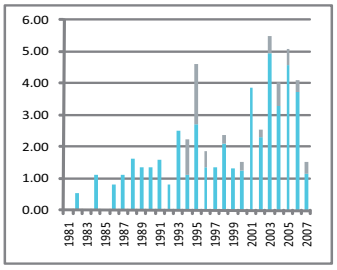
Cleft lip with or without cleft palate



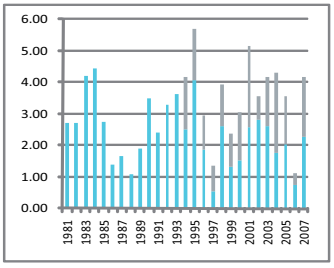
Oesophageal atresia/stenosis with or without fistula



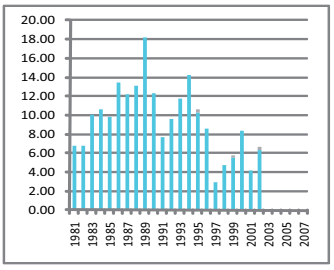
Small intestine atresia/stenosis



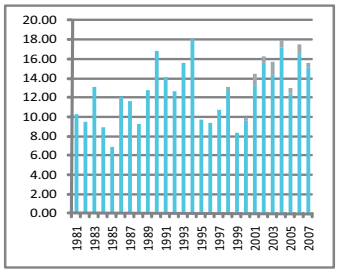
Anorectal atresia/stenosis



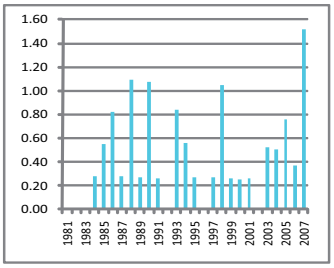
Undescended testis



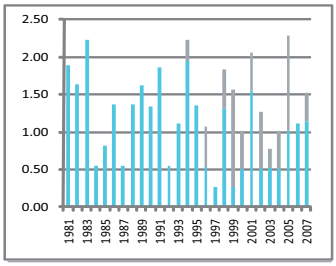
Hypospadias



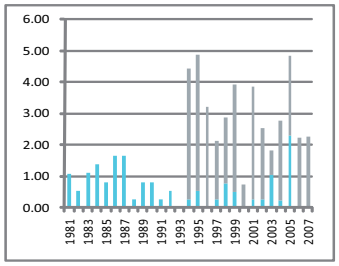
Epispadias



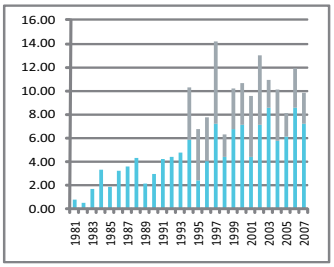
Indeterminate sex



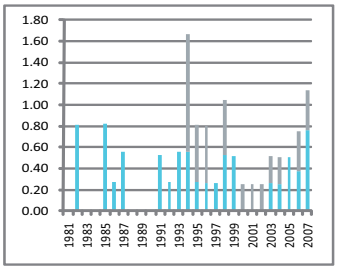
Renal agenesis



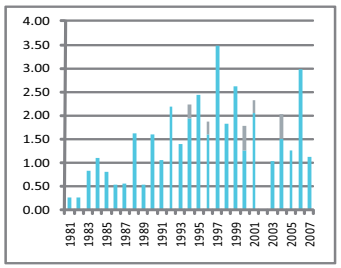
Cystic kidney



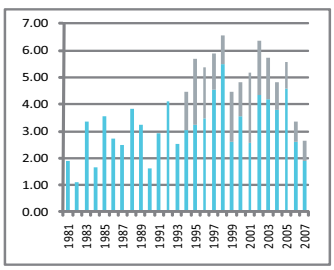
Bladder exstrophy



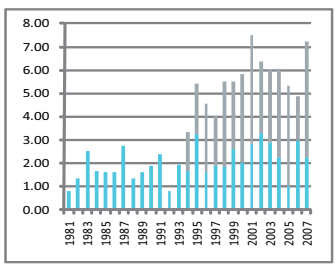
Polydactyly, preaxial



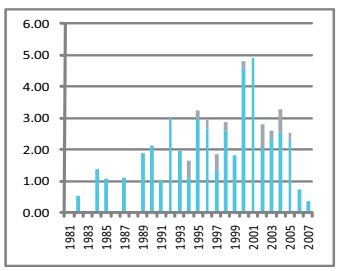
Diaphragmatic hernia



Omphalocele



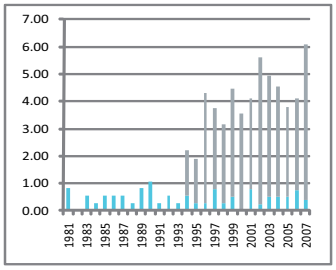
Gastroschisis



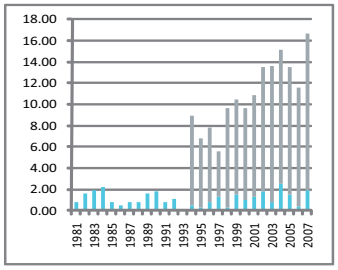
Note: L+S rates, ToP rates

France: Paris

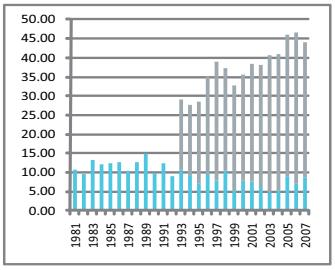
Trisomy 13



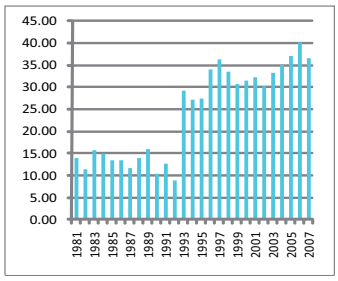
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

France: (REMERA)

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

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

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

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

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

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

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

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E-mail: emmanuelle.amar@orange.fr

France: REMERA, 2007

Live births (LB)	57,216
Stillbirths (SB)	528
Total births	57,744
Number of terminations of pregnancy (ToP) for birth defects	414

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	22	3.98
Spina bifida	6	1	30	6.41
Encephalocele	3	0	8	1.90
Microcephaly	10	0	5	2.60
Holoprosencephaly	1	0	7	1.39
Hydrocephaly	16	2	26	7.62
Anophthalmos	0	0	1	0.17
Microphthalmos	1	1	3	0.87
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	-3	1	1	0.87
Microtia	2	0	0	0.35
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	12	0	5	2.94
Tetralogy of Fallot	8	0	2	1.73
Hypoplastic left heart syndrome	10	3	26	6.75
Coarctation of aorta	7	0	3	1.73
Choanal atresia, bilateral	3	0	1	0.69
Cleft palate without cleft lip	27	1	9	6.41
Cleft lip with or without cleft palate	40	0	10	8.66
Oesophageal atresia/stenosis with or without fistula	10	1	2	2.25
Small intestine atresia/stenosis	5	2	1	1.39
Anorectal atresia/stenosis	0	0	0	0.00
Undescended testis (36 weeks of gestation or later)	4	0	0	0.69
Hypospadias	59	0	2	10.56
Epispadias	1	0	0	0.17
Indeterminate sex	3	0	1	0.69
Renal agenesis	18	2	6	4.50
Cystic kidney	31	0	16	8.14
Bladder exstrophy	1	0	3	0.69
Polydactyly, preaxial	40	2	7	8.49
Total Limb reduction defects (include unspecified)	16	0	15	5.37
Transverse	11	0	6	2.94
Preaxial	5	0	3	1.39
Postaxial	0	0	2	0.35
Intercalary	0	0	3	0.52
Mixed	0	0	1	0.17
Unspecified	0	0	0	0.00
Diaphragmatic hernia	14	1	8	3.98
Omphalocele	7	0	11	3.12
Gastroschisis	8	0	3	1.90
Unspecified Omphalocele/Gastroschisis	0	0	6	1.04
Prune belly sequence	0	0	3	0.52
Trisomy 13	2	0	10	2.08
Trisomy 18	3	2	34	6.75
Down syndrome, all ages (include age unknown)	29	1	112	24.59
<20	0	0	0	0.00
20-24	0	0	6	7.79
25-29	4	0	12	8.17
30-34	6	0	33	21.02
35-39	11	1	35	52.59
40-44	3	0	18	121.88
45+	0	0	4	634.92
unknown	5	0	4	---

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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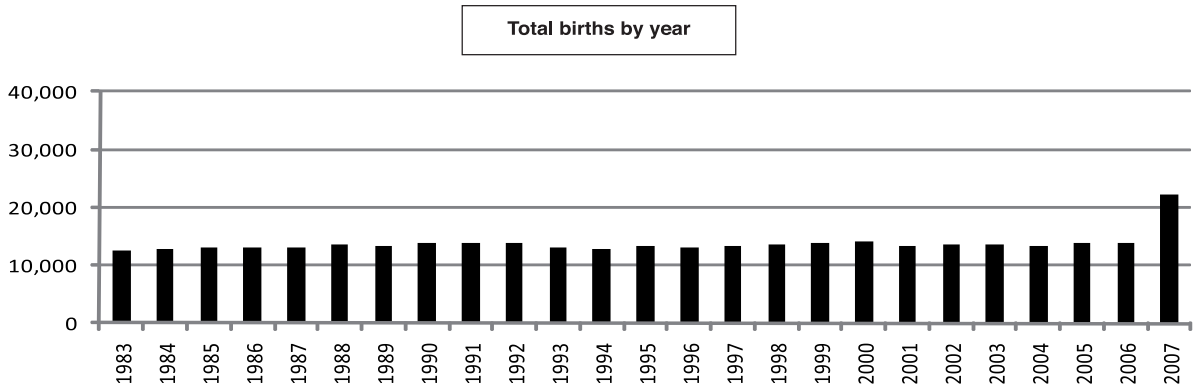
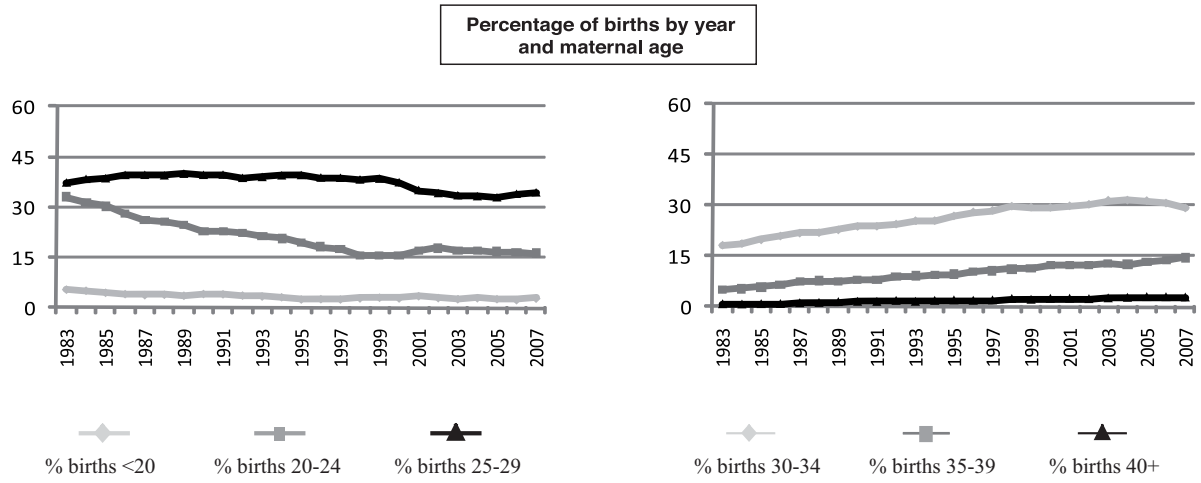
France: Strasbourg





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	18	94.7	Cystic kidney	16	38.1
Spina bifida	36	92.3	Limb reduction defects	13	28.9
Encephalocele	3	100.0	Diaphragmatic hernia	8	38.1
Holoprosencephaly	9	81.8	Omphalocele	5	55.6
Hydrocephaly	20	76.9	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	5	45.5	Trisomy 13	8	80.0
Cleft palate without cleft lip	4	9.8	Trisomy 18	25	96.2
Cleft lip with or without cleft palate	13	25.5	Down syndrome	90	70.9
Renal agenesis	2	11.1			

Total ToPs with births defects = 317 (Ratio ToPs/Births: 6.34 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

France: Strasbourg, 2007

Live births (LB)	22,093
Stillbirths (SB)	149
Total births	22,242
Number of terminations of pregnancy (ToP) for birth defects	145

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	10	4.50
Spina bifida	2	0	15	7.64
Encephalocele	0	0	0	0.00
Microcephaly	7	0	1	3.60
Holoprosencephaly	1	0	2	1.35
Hydrocephaly	6	0	14	8.99
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	0	0.90
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.45
Microtia	5	0	1	2.70
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	0	3	4.05
Tetralogy of Fallot	5	0	5	4.50
Hypoplastic left heart syndrome	4	0	1	2.25
Coarctation of aorta	13	0	1	6.29
Choanal atresia, bilateral	1	0	1	0.90
Cleft palate without cleft lip	15	0	2	7.64
Cleft lip with or without cleft palate	14	1	4	8.54
Oesophageal atresia/stenosis with or without fistula	11	0	1	5.40
Small intestine atresia/stenosis	6	0	1	3.15
Anorectal atresia/stenosis	8	0	1	4.05
Undescended testis (36 weeks of gestation or later) (*)	2	0	0	0.90
Hypospadias (**)	33	0	0	14.84
Epispadias	1	0	0	0.45
Indeterminate sex	0	0	0	0.00
Renal agenesis	0	3	0	1.35
Cystic kidney	10	0	9	8.54
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	8	0	0	3.60
Total Limb reduction defects (include unspecified)	14	0	5	8.54
Transverse	5	0	2	3.15
Preaxial	2	0	2	1.80
Postaxial	2	0	0	0.90
Intercalary	4	0	1	2.25
Mixed	1	0	0	0.45
Unspecified	0	0	0	0.00
Diaphragmatic hernia	7	0	3	4.50
Omphalocele	1	0	0	0.45
Gastroschisis	5	0	0	2.25
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	2	0.90
Trisomy 13	1	0	2	1.35
Trisomy 18	0	0	8	3.60
Down syndrome, all ages (include age unknown)	17	2	47	29.67
<20	0	0	0	0.00
20-24	4	0	0	11.07
25-29	2	0	10	15.72
30-34	4	0	6	15.40
35-39	4	1	19	73.94
40-44	3	1	11	258.18
45+	0	0	1	416.67
unknown	0	0	0	---

(*) Only bilateral and associated cryptorcisim are registered
(**) All sorts of hypospadias are registered

France: Strasbourg, Previous years rates 1983 - 2007

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

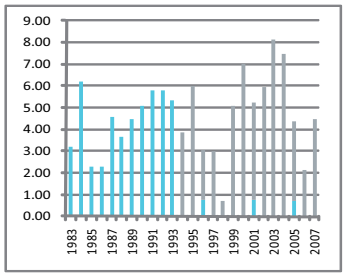
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births			**64,896**	**68,326**	**65,737**	**68,608**	**76,846**
Anencephaly			3.70	4.98	4.26	4.81	5.21
Spina bifida			4.93	3.37	4.41	7.14	6.77
Encephalocele			1.08	1.17	2.59	0.87	1.04
Microcephaly			nr	nr	2.47*	0.58	2.34
Holoprosencephaly			nr	nr	1.90*	2.04	2.86
Hydrocephaly			6.01	4.10	7.00	4.37	5.34
Anophthalmos			0.46	0.15	0.61	0.44	0.13
Microphthalmos			3.08	1.17	2.89	1.75	1.43
Unspecified Anophthalmos / Microphthalmos			0.00	0.00	0.00	0.00	0.00
Anotia			0.31	0.00	0.91	0.00	0.65
Microtia			1.23	1.17	1.83	2.04	1.82
Unspecified Anotia / Microtia			0.00	0.00	0.00	0.00	0.00
Transposition of great vessels			5.09	4.54	5.17	6.85	3.25
Tetralogy of Fallot			2.47	4.24	3.96	3.64	4.29
Hypoplastic left heart syndrome			2.77	3.22	3.35	2.92	2.34
Coarctation of aorta			6.01	3.51	5.32	3.79	4.16
Choanal atresia, bilateral			nr	nr	nr	0.29	0.52
Cleft palate without cleft lip			8.94	9.37	8.52	6.56	7.81
Cleft lip with or without cleft palate			9.09	11.12	13.23	12.24	11.97
Oesophageal atresia / stenosis with or without fistula			2.16	3.07	2.43	3.79	4.16
Small intestine atresia / stenosis			nr	nr	1.71*	2.33	2.21
Anorectal atresia / stenosis			5.24	5.85	5.17	5.54	4.55
Undescended testis (36 weeks of gestation or later)			nr	nr	nr	nr	nr
Hypospadias			19.42	25.32	24.95	22.15	19.00
Epispadias			nr	nr	0.19*	0.15	0.39
Indeterminate sex			nr	nr	0.38*	0.44	0.91
Renal agenesis			nr	nr	3.23*	8.31	4.68
Cystic kidney			nr	nr	7.79*	8.16	7.42
Bladder exstrophy			nr	nr	0.57*	0.15	0.39
Polydactyly, preaxial			nr	nr	3.23*	4.96	2.73
‘Total Limb reduction defects (include unspecified)			6.16	7.76	10.95	8.16	8.85
Transverse			4.31	4.68	4.26	4.96	3.25
Preaxial			1.39	1.90	1.83	0.58	1.43
Postaxial			0.15	0.59	0.15	0.73	0.78
Intercalary			0.00	0.29	1.06	0.29	0.78
Mixed			0.31	0.29	0.61	1.02	2.34
Unspecified			0.00	0.00	0.00	0.58	0.00
Diaphragmatic hernia			4.01	4.83	4.11	4.52	4.68
Omphalocele			3.08	3.51	5.02	2.77	2.34
Gastroschisis			1.85	1.90	3.19	1.75	1.56
Unspecified Omphalocele / Gastroschisis			0.00	0.59	1.52	1.31	0.78
Prune belly sequence			nr	nr	0.19*	0.73	0.65
Trisomy 13			nr	nr	2.09*	1.60	2.86
Trisomy 18			nr	nr	3.42*	5.25	6.25
Down syndrome, all ages (include age unknown)			11.40	19.32	33.77	21.57	25.77
<20			6.55	21.81	10.15	13.82	0.00
20-24			7.76	11.13	9.39	12.54	6.25
25-29			6.38	8.54	17.14	5.97	9.29
30-34			9.25	19.40	26.59	13.75	17.42
35-39			46.15	60.07	115.88	70.87	73.71
40-44			191.57	208.55	376.68	127.35	200.30
45+			294.12	227.27	0.00	0.00	123.46
unknown			---	---	---	---	---

nr = not reported
* data include less than 5 years

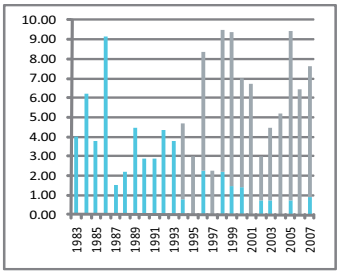
France: Strasbourg

'Time trends 1983-2007 (Birth prevalence rates per 10,000)

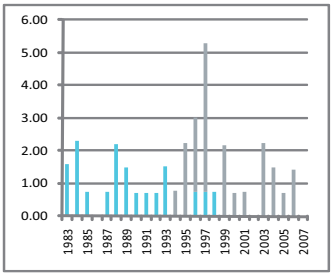
Anencephaly



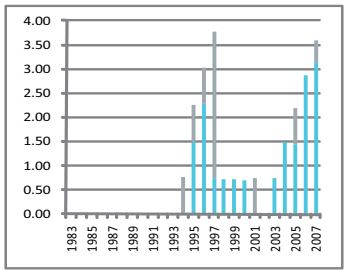
Spina Bifida



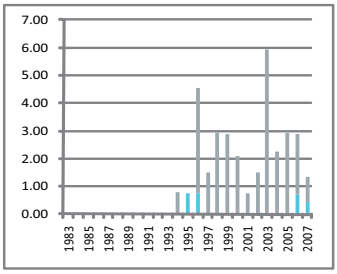
Encephalocele



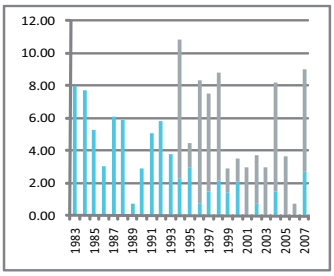
Microcephaly



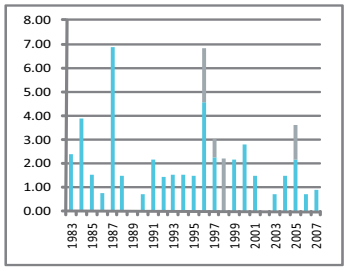
Holoprosencephaly



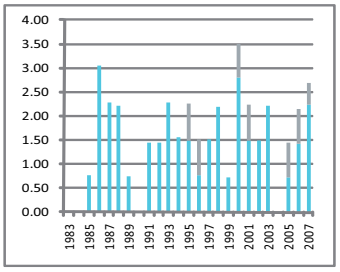
Hydrocephaly



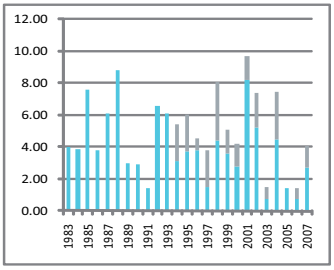
Microphthalmos



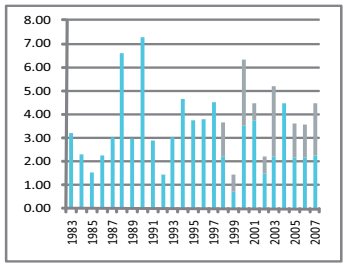
Microtia



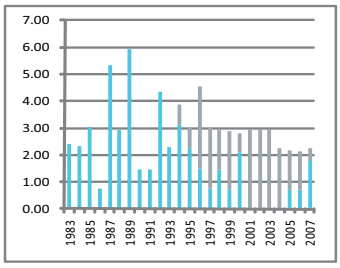
Transposition of great vessels



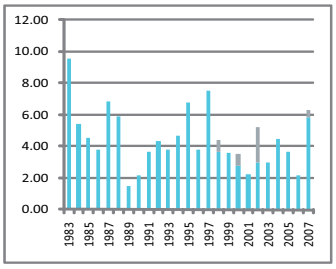
Tetralogy of Fallot



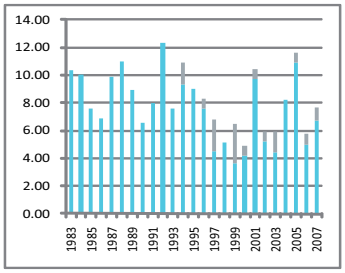
Hypoplastic left heart syndrome



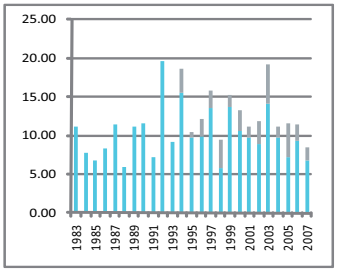
Coarctation of aorta



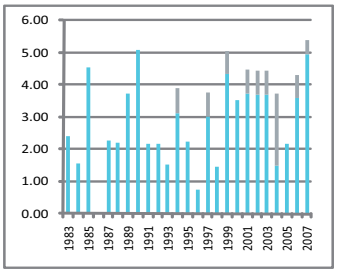
Cleft palate without cleft lip



Cleft lip with or without cleft palate



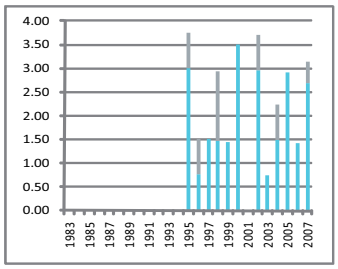
Oesophageal atresia/stenosis with or without fistula



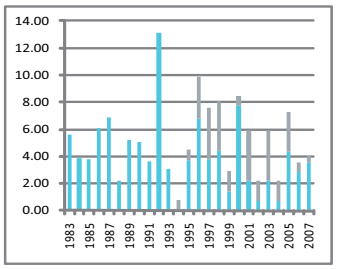
Note: L+S rates, ToP rates

France: Strasbourg

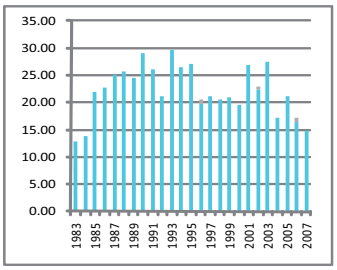
Small intestine atresia/stenosis



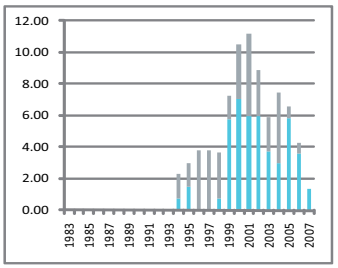
Anorectal atresia/stenosis



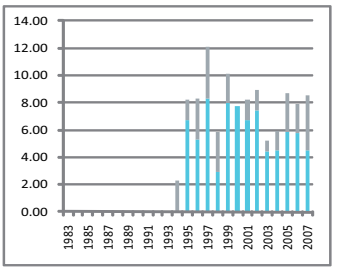
Hypospadias



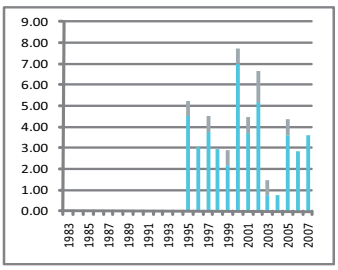
Renal agenesis



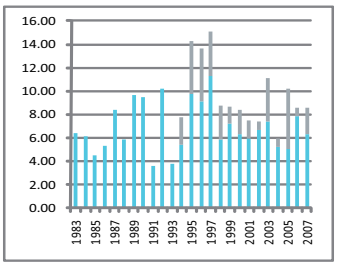
Cystic kidney



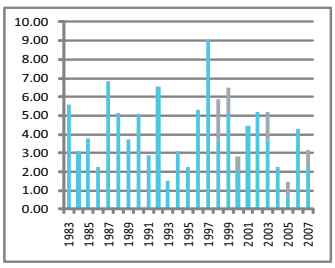
Polydactyly, preaxial



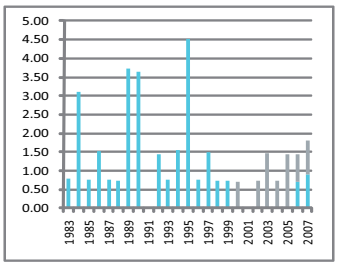
Limb reduction defects



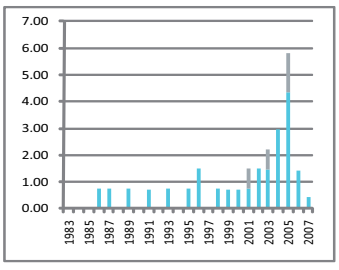
Limb reduction defects - transverse



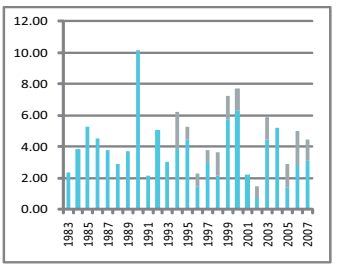
Limb reduction defects - preaxial



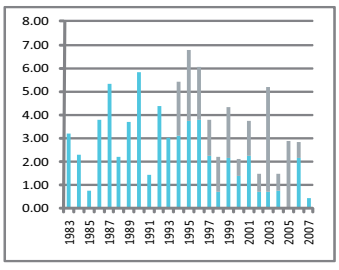
Limb reduction defects - mixed



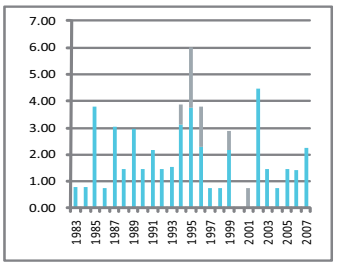
Diaphragmatic hernia



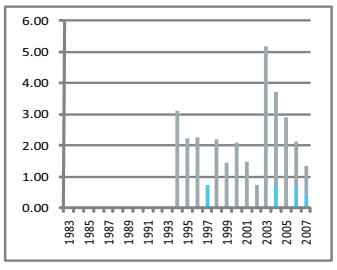
Omphalocele



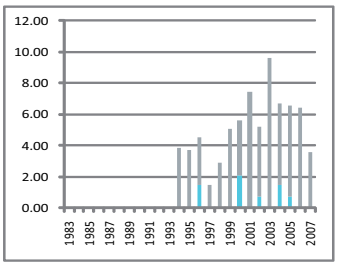
Gastroschisis



Trisomy 13



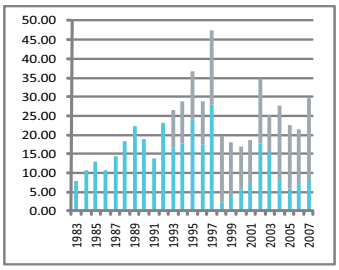
Trisomy 18



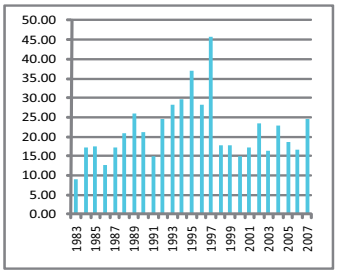
Note: L+S rates, ToP rates

France: Strasbourg

Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Germany: Saxony-Anhalt
Malformation Monitoring Center 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 2.38 million inhabitants (31.12.2008) and annual births at a rate of about 17 000 children (2008). The survey system is multi-centric and based on population.

Legislation and funding:
1980 to 1989: Ministry of Health of the former German Democratic Republic 1990 to 1992: Medical Faculty, Magdeburg 1993 to 1995: Ministry of Health, Federal Republic of Germany since 1995: Ministry of Labour, Women, Health and Social Security of the Federal State of Saxony-Anhalt. The Malformation Monitoring is working in order of Ministry of Labour, Women, Health and Social Security of the Federal State of Saxony-Anhalt.

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).

Addresses and Staff:
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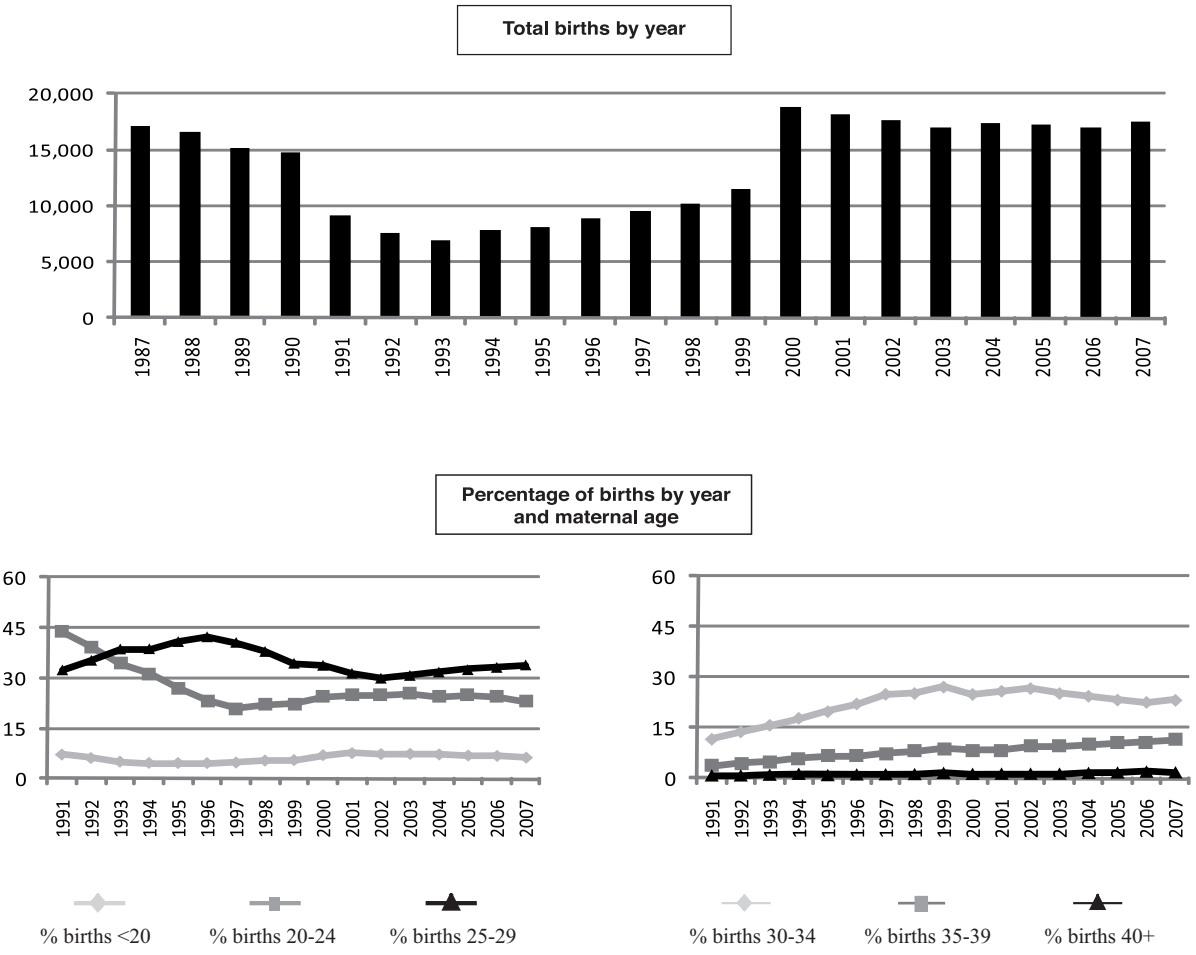
D-39120 Magdeburg, Germany
E-mail: Anke.Rissmann@med.ovgu.de
Website: www.angeborene-fehlbildungen.com

Germany: Saxony Anhalt



Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	7	87.5	Cystic kidney	8	15.7
Spina bifida	12	52.2	Limb reduction defects	10	28.6
Encephalocele	1	33.3	Diaphragmatic hernia	3	27.3
Holoprosencephaly	4	66.7	Omphalocele	13	61.9
Hydrocephaly	9	33.3	Gastroschisis	4	17.4
Hypoplastic left heart syndrome	6	46.2	Trisomy 13	6	85.7
Cleft palate without cleft lip	4	7.3	Trisomy 18	16	94.1
Cleft lip with or without cleft palate	11	14.7	Down syndrome	42	53.8
Renal agenesis	2	50.0			

Total ToPs with births defects = 275 (Ratio ToPs/Births: 5.32 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Germany: Saxony Anhalt, 2007

Live births (LB)	17,387
Stillbirths (SB)	83
Total births	17,470
Number of terminations of pregnancy (ToP) for birth defects	98

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	2	1.72
Spina bifida	3	0	4	4.01
Encephalocele	2	0	1	1.72
Microcephaly	22	5	1	16.03
Holoprosencephaly	1	0	0	0.57
Hydrocephaly	3	2	4	5.15
Anophthalmos	0	0	0	0.00
Microphthalmos	1	0	0	0.57
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	2	0	0	1.14
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	5	0	0	2.86
Tetralogy of Fallot	2	0	0	1.14
Hypoplastic left heart syndrome	1	1	2	2.29
Coarctation of aorta	7	0	3	5.72
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	13	2	0	8.59
Cleft lip with or without cleft palate	23	1	3	15.46
Oesophageal atresia/stenosis with or without fistula	4	0	0	2.29
Small intestine atresia/stenosis	3	0	0	1.72
Anorectal atresia/stenosis	9	0	1	5.72
Undescended testis (36 weeks of gestation or later)	9	0	0	5.15
Hypospadias	10	0	0	5.72
Epispadias	2	0	0	1.14
Indeterminate sex	1	0	0	0.57
Renal agenesis	1	0	0	0.57
Cystic kidney	16	0	1	9.73
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	13	0	1	8.01
Total Limb reduction defects (include unspecified)	14	0	5	10.88
Transverse	7	0	0	4.01
Preaxial	2	0	0	1.14
Postaxial	3	0	0	1.72
Intercalary	0	0	0	0.00
Mixed	2	0	5	4.01
Unspecified	0	0	0	0.00
Diaphragmatic hernia	2	0	1	1.72
Omphalocele	4	0	2	3.43
Gastroschisis	5	0	0	2.86
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	1	1.14
Trisomy 18	0	0	6	3.43
Down syndrome, all ages (include age unknown)	14	0	11	14.31
<20	0	0	0	0.00
20-24	3	0	2	12.48
25-29	2	0	2	6.76
30-34	4	0	2	14.81
35-39	5	0	3	39.62
40-44	0	0	2	63.90
45+	0	0	0	0.00
unknown	0	0	0	---

Germany: Saxony Anhalt, Previous years rates 1980 - 2007

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

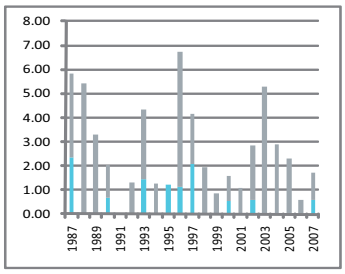
	1974-1977	1978-1982*	1983-1987*	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**53,689**	**85,969**	**63,344**	**41,415**	**76,377**	**86,076**	
Anencephaly	1.12	3.14	2.84	3.62	1.70	2.56	
Spina bifida	3.17	8.72	8.21	5.55	6.28	5.92	
Encephalocele	0.19	1.16	0.95	1.69	1.96	1.16	
Microcephaly	nr	2.33	2.37	4.59	9.43	20.68	
Holoprosencephaly	nr	1.75	1.26	0.97	0.79	1.74	
Hydrocephaly	nr	4.66	5.21	10.62	9.17	5.11	
Anophthalmos	nr	0.00	0.16	0.72	0.13	0.23	
Microphthalmos	nr	1.17	1.11	1.93	0.26	0.58	
Unspecified Anophthalmos / Microphthalmos	nr	0.00	0.00	0.00	0.00	0.00	
Anotia	nr	0.00	0.00	0.24	0.13	0.23	
Microtia	nr	0.00	0.16	0.00	1.18	0.81	
Unspecified Anotia / Microtia	nr	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	nr	2.91	2.53	4.59	5.50	4.65	
Tetralogy of Fallot	nr	0.58	0.63	2.41	3.14	3.37	
Hypoplastic left heart syndrome	nr	5.24	3.63	4.10	4.32	2.21	
Coarctation of aorta	nr	1.75	1.89	2.66	2.75	4.18	
Choanal atresia, bilateral	nr	2.33	0.95	0.97	0.65	0.35	
Cleft palate without cleft lip	nr	4.66	5.21	6.52	10.61	9.41	
Cleft lip with or without cleft palate	nr	9.32	14.68	15.69	16.50	15.22	
Oesophageal atresia / stenosis with or without fistula	nr	2.91	2.68	2.17	2.88	2.32	
Small intestine atresia / stenosis	nr	1.17	1.58	2.41	2.23	1.97	
Anorectal atresia / stenosis	nr	2.91	4.10	1.93	3.27	3.95	
Undescended testis (36 weeks of gestation or later)	nr	6.99	15.79	13.76	10.47	10.69	
Hypospadias	nr	11.65	15.00	19.80	11.39	8.36	
Epispadias	nr	0.00	0.32	0.97	0.13	0.58	
Indeterminate sex	nr	0.58	0.32	0.00	1.44	0.35	
Renal agenesis	nr	0.00	1.74	1.93	2.49	1.74	
Cystic kidney	nr	2.91	1.74	4.35	3.80	9.41	
Bladder exstrophy	nr	1.17	0.47	0.72	0.00	0.23	
Polydactyly, preaxial	nr	0.00	0.47	3.86	4.58	3.60	
‘Total Limb reduction defects (include unspecified)	nr	4.66	6.63	5.55	7.86	7.78	
Transverse	nr	nr	nr	nr	3.47*	2.56	
Preaxial	nr	nr	nr	nr	0.18*	0.70	
Postaxial	nr	nr	nr	nr	0.00*	0.35	
Intercalary	nr	nr	nr	nr	1.83*	0.93	
Mixed	nr	nr	nr	nr	1.46*	2.44	
Unspecified	nr	nr	nr	nr	0.00*	0.81	
Diaphragmatic hernia	nr	1.17	1.89	0.48	2.36	2.44	
Omphalocele	nr	4.66	4.42	2.66	2.75	3.95	
Gastroschisis	nr	1.17	1.74	2.90	3.01	4.88	
Unspecified Omphalocele / Gastroschisis	nr	nr	nr	nr	0.18*	0.00	
Prune belly sequence	nr	nr	0.32	0.72	1.31	0.46	
Trisomy 13	0.00	0.58	0.32	1.69	1.44	1.05	
Trisomy 18	0.56	1.05	0.95	1.69	2.09	3.83	
Down syndrome, all ages (include age unknown)	8.94	8.03	10.26	12.80	17.15	15.34	
<20	nr	nr	nr	nr	5.00*	3.37	
20-24	nr	nr	nr	nr	5.93*	9.06	
25-29	nr	nr	nr	nr	10.94*	6.80	
30-34	nr	nr	nr	nr	12.06*	14.21	
35-39	nr	nr	nr	nr	61.27*	43.33	
40-44	nr	nr	nr	nr	147.84*	149.15	
45+	nr	nr	nr	nr	666.66*	163.93	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

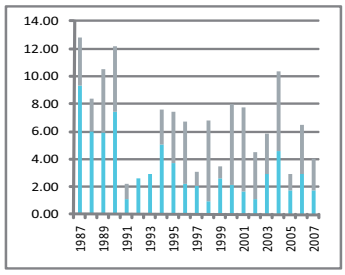
Germany: Saxony Anhalt

'Time trends 1980-2007 (Birth prevalence rates per 10,000)

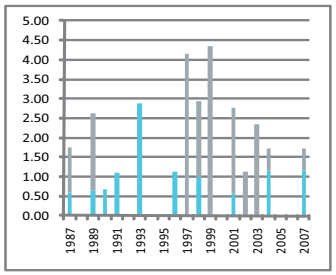
Anencephaly



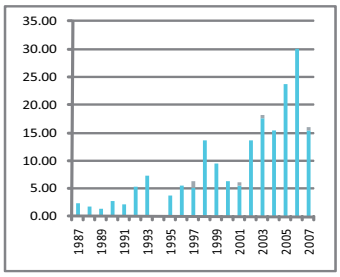
Spina Bifida



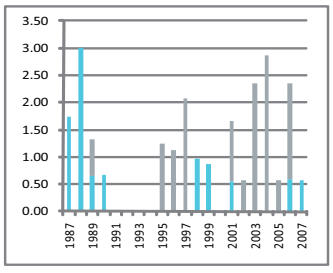
Encephalocele



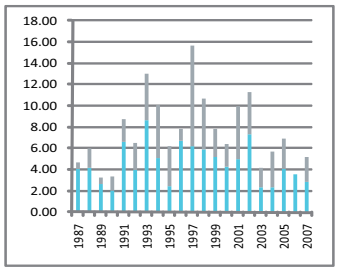
Microcephaly



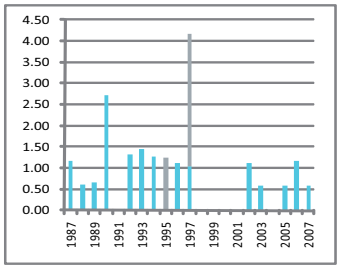
Holoprosencephaly



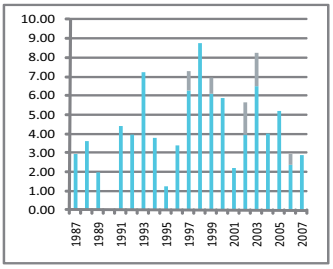
Hydrocephaly



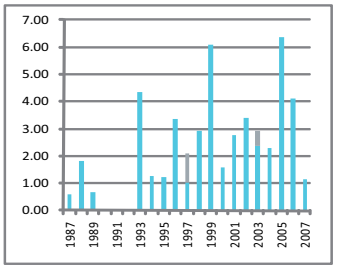
Microphthalmos



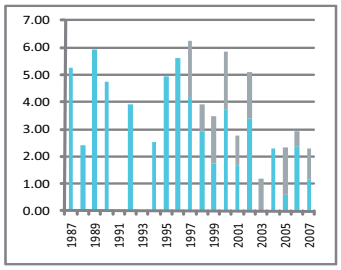
Transposition of great vessels



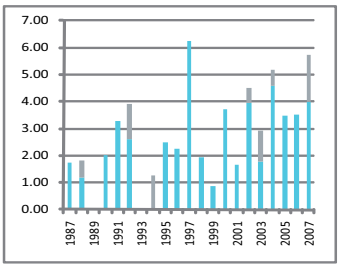
Tetralogy of Fallot



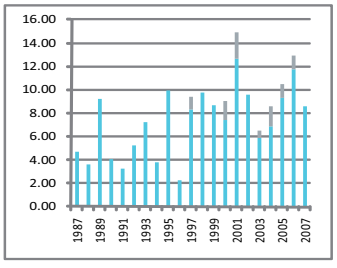
Hypoplastic left heart syndrome



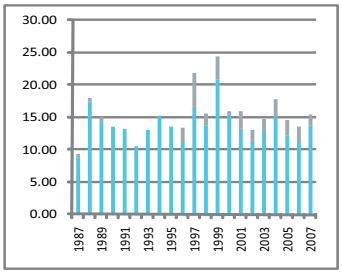
Coarctation of aorta



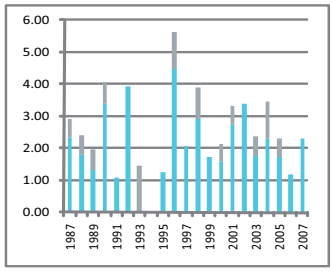
Cleft palate without cleft lip



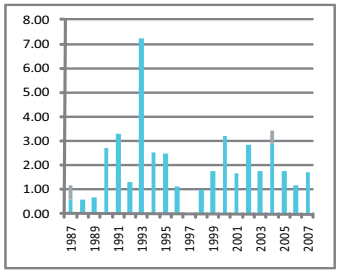
Cleft lip with or without cleft palate



Oesophageal atresia/stenosis with or without fistula



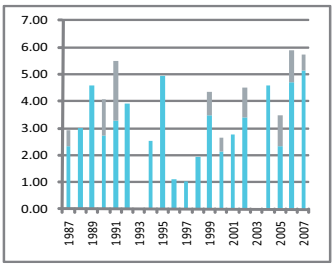
Small intestine atresia/stenosis



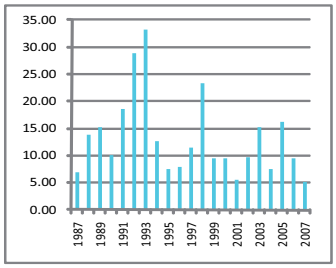
Note: L+S rates, ToP rates

Germany: Saxony Anhalt

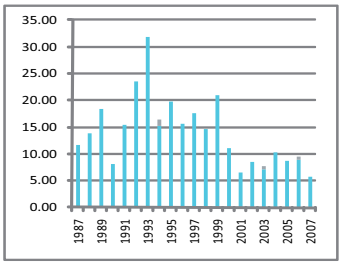
Anorectal atresia/stenosis



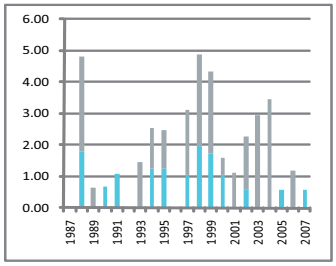
Undescended testis



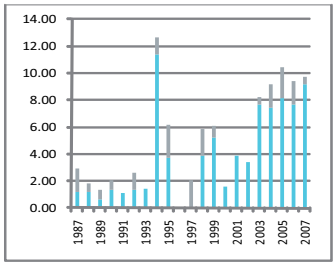
Hypospadias



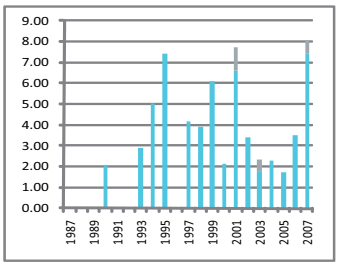
Renal agenesis



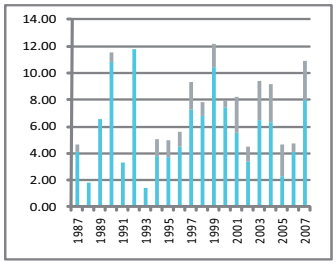
Cystic kidney



Polydactyly, preaxial



Limb reduction defects



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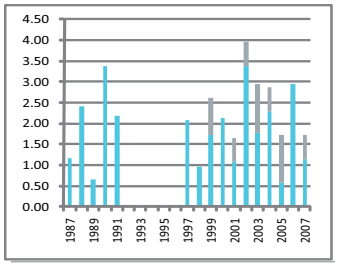
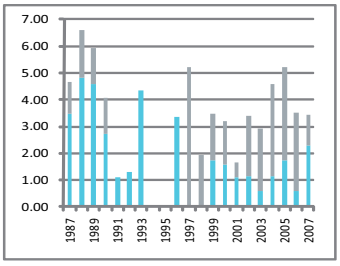
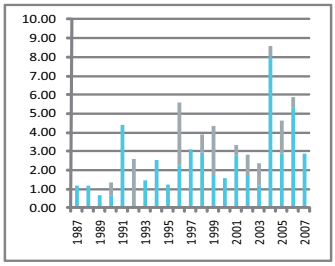


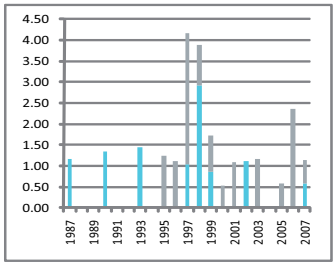
Omphalocele



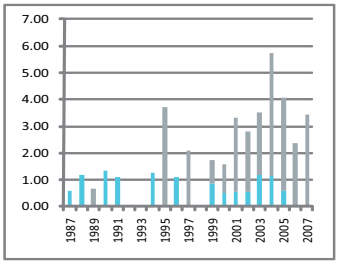
Gastroschisis



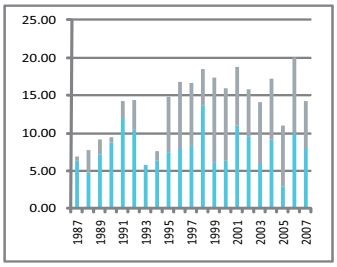
Trisomy 13



Trisomy 18



Down Syndrome



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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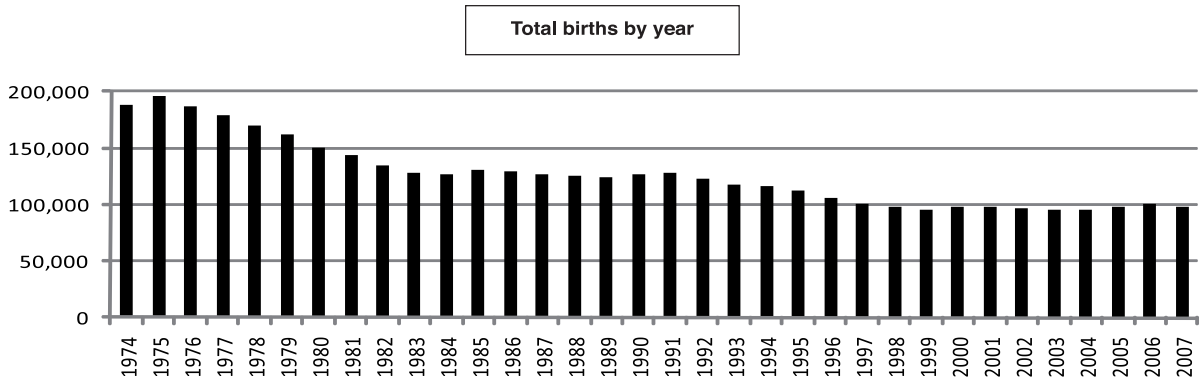
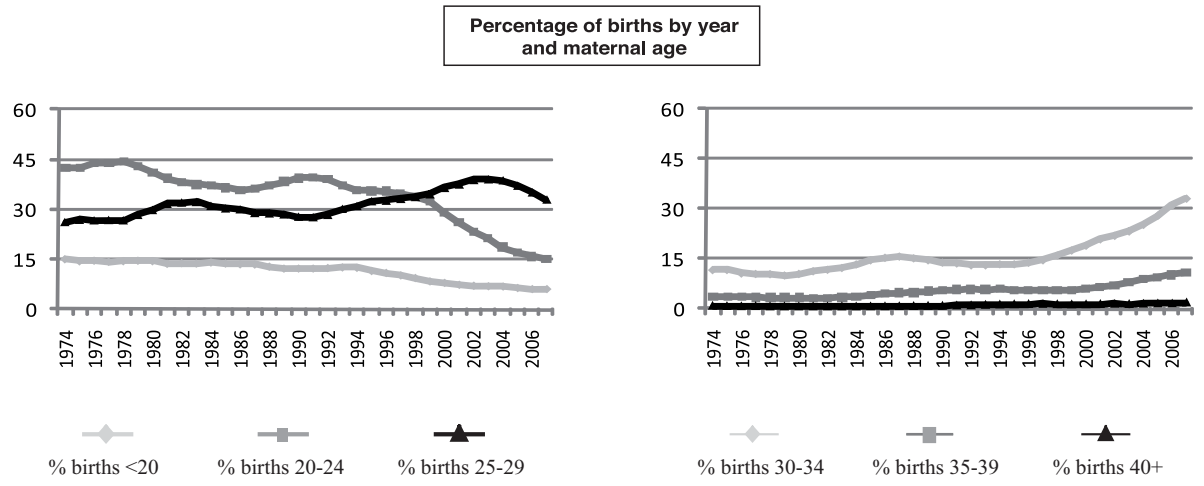
Erzsebet Horvath-Puho, PhD
Melinda Csaky-Szunyogh, MSc

Hungary





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	49	89.1	Cystic kidney	34	27.9
Spina bifida	79	61.7	Limb reduction defects	13	14.4
Encephalocele	6	46.2	Diaphragmatic hernia	11	19.3
Holoprosencephaly	8	72.7	Omphalocele	16	47.1
Hydrocephaly	66	44.9	Gastroschisis	17	50.0
Hypoplastic left heart syndrome	15	21.1	Trisomy 13	21	84.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	57	83.8
Cleft lip with or without cleft palate	6	2.7	Down syndrome	238	50.7
Renal agenesis	10	41.7			

Total ToPs with births defects = 1,070 (Ratio ToPs/Births: 3.61 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Hungary: 2007

Isolated and non-isolated cases (*)

Live births (LB)	97,613
Stillbirths (SB)	485
Total births	98,098
Number of terminations of pregnancy (ToP) for birth defects	373

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	20	2.24
Spina bifida	18	0	37	5.61
Encephalocele	3	0	5	0.82
Microcephaly	23	0	0	2.34
Holoprosencephaly	3	0	6	0.92
Hydrocephaly	17	0	29	4.69
Anophthalmos	3	0	0	0.31
Microphthalmos	10	0	0	1.02
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	10	0	0	1.02
Microtia	1	0	0	0.10
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	38	0	3	4.18
Tetralogy of Fallot	29	0	0	2.96
Hypoplastic left heart syndrome	28	0	7	3.57
Coarctation of aorta	46	0	0	4.69
Choanal atresia, bilateral	2	0	0	0.20
Cleft palate without cleft lip	40	0	0	4.08
Cleft lip with or without cleft palate	82	0	6	8.97
Oesophageal atresia/stenosis with or without fistula	16	0	1	1.73
Small intestine atresia/stenosis	19	0	1	2.04
Anorectal atresia/stenosis	30	0	1	3.16
Undescended testis (36 weeks of gestation or later)	204	0	0	20.80
Hypospadias	282	0	0	28.75
Epispadias (**)	nr	nr	nr	nr
Indeterminate sex	4	0	0	0.41
Renal agenesis	7	0	6	1.33
Cystic kidney	39	0	17	5.71
Bladder exstrophy	5	0	0	0.51
Polydactyly, preaxial	103	0	0	10.50
Total Limb reduction defects (include unspecified)	17	0	7	2.45
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	0	3	2.34
Omphalocele	10	0	8	1.83
Gastroschisis	2	0	7	0.92
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.10
Trisomy 13	2	0	8	1.02
Trisomy 18	5	0	21	2.65
Down syndrome, all ages (include age unknown)	75	0	81	15.90
<20	3	0	1	6.64
20-24	6	0	1	4.75
25-29	23	0	9	9.88
30-34	22	0	18	12.31
35-39	15	0	35	47.11
40-44	6	0	17	125.75
unknown	0	0	0	---

(*) This table is given for the first time this year.Table on ToPs and Tabulations and graphs for previous years include only isolated cases
(**) Epispadias included in Hypospadias
nr = not reported

Hungary: 2007

Isolated cases only

Live births (LB)	97,613
Stillbirths (SB)	485
Total births	98,098
Number of terminations of pregnancy (ToP) for birth defects	373

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	0	17	1.83
Spina bifida	12	0	34	4.69
Encephalocele	3	0	3	0.61
Microcephaly	17	0	0	1.73
Holoprosencephaly	0	0	4	0.41
Hydrocephaly	14	0	20	3.47
Anophthalmos	1	0	0	0.10
Microphthalmos	6	0	0	0.61
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	6	0	0	0.61
Microtia	1	0	0	0.10
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	32	0	2	3.47
Tetralogy of Fallot	20	0	0	2.04
Hypoplastic left heart syndrome	26	0	4	3.06
Coarctation of aorta	41	0	0	4.18
Choanal atresia, bilateral	2	0	0	0.20
Cleft palate without cleft lip	31	0	0	3.16
Cleft lip with or without cleft palate	67	0	1	6.93
Oesophageal atresia/stenosis with or without fistula	12	0	0	1.22
Small intestine atresia/stenosis	15	0	1	1.63
Anorectal atresia/stenosis	18	0	0	1.83
Undescended testis (36 weeks of gestation or later)	189	0	0	19.27
Hypospadias (*)	250	0	0	25.48
Epispadias	nr	nr	nr	nr
Indeterminate sex	3	0	0	0.31
Renal agenesis	5	0	6	1.12
Cystic kidney	26	0	14	4.08
Bladder exstrophy	4	0	0	0.41
Polydactyly, preaxial	86	0	0	8.77
Total Limb reduction defects (include unspecified)	14	0	5	1.94
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	14	0	2	1.63
Omphalocele	6	0	5	1.12
Gastroschisis	2	0	7	0.92
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	1	0	0	0.10
Trisomy 13	2	0	8	1.02
Trisomy 18	5	0	21	2.65
Down syndrome, all ages (include age unknown)	75	0	81	15.90
<20	3	0	1	6.64
20-24	6	0	1	4.75
25-29	23	0	9	9.88
30-34	22	0	18	12.31
35-39	15	0	35	47.11
40+	6	0	17	125.75
unknown	0	0	0	---

(*) Epispadias included in Hypospadias
nr = not reported

Hungary: Previous years rates 1974 - 2007

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

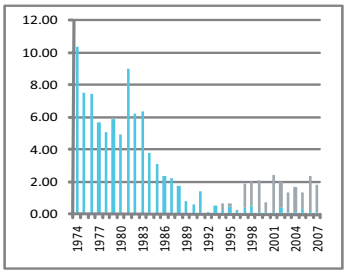
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**749,872**	**759,671**	**641,080**	**625,410**	**552,410**	**486,032**	**487,250**
Anencephaly	7.79	6.17	3.59	0.96	0.80	1.87	1.72
Spina bifida	12.03	8.11	7.58	3.57	1.88	3.15	3.80
Encephalocele	nr	1.67	1.58	0.72	0.31	0.78	0.49
Microcephaly	nr	1.49*	1.05	0.77	0.69	0.53	1.23
Holoprosencephaly	nr	0.21*	0.28	0.10	0.14	0.95	0.57
Hydrocephaly	7.61	5.05	3.53	2.59	1.59	2.63	4.49
Anophthalmos	0.13	0.08	0.06	0.05	0.07	0.02	0.06
Microphthalmos	0.09	0.26	0.16	0.10	0.05	0.08	0.33
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.11	0.08	0.17	0.24	0.24	0.62	0.64
Microtia	0.04	0.05	0.02	0.00	0.04	0.06	0.12
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	1.01	1.70	1.89	0.92	1.42	2.26
Tetralogy of Fallot	1.08	1.61	0.92	1.09	1.07	1.81	2.34
Hypoplastic left heart syndrome	nr	0.45	0.39	0.98	0.43	0.97	1.91
Coarctation of aorta	0.92	1.82	2.54	2.00	1.79	1.36	2.67
Choanal atresia, bilateral	nr	0.16*	0.11	0.19	0.07	0.04	0.16
Cleft palate without cleft lip	3.49	4.75	4.01	3.61	2.68	3.19	3.41
Cleft lip with or without cleft palate	10.58	11.76	10.09	9.21	7.15	6.81	7.45
Oesophageal atresia / stenosis with or without fistula	2.08	1.88	1.67	1.73	0.94	0.95	1.38
Small intestine atresia / stenosis	nr	1.58*	1.25	1.23	0.65	0.60	1.29
Anorectal atresia / stenosis	nr	2.34	2.12	1.46	1.21	0.78	1.66
Undescended testis (36 weeks of gestation or later)	nr	15.56*	18.05	15.80	13.07	10.84	17.42
Hypospadias	16.52	17.35	21.11	21.84	19.33	21.36	25.63
Epispadias	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	nr	0.25*	0.28	0.35	0.13	0.23	0.47
Renal agenesis	nr	1.32	0.87	1.18	0.14	0.19	0.76
Cystic kidney	nr	0.00*	0.11	0.40	0.76	1.93	3.78
Bladder exstrophy	nr	0.30*	0.48	0.18	0.02	0.06	0.21
Polydactyly, preaxial	nr	0.63*	1.83	1.63	2.19	8.27	8.17
‘Total Limb reduction defects (include unspecified)	nr	4.75*	4.12	3.41	2.95	2.98	3.14
Transverse	nr	nr	nr	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr	nr	nr	nr
Mixed	nr	nr	nr	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	2.48	1.74	2.12	2.19	0.83	0.58	1.42
Omphalocele	nr	2.45*	1.73	0.90	0.71	0.93	1.19
Gastroschisis	nr	0.52*	0.50	0.62	0.42	0.84	0.92
Unspecified Omphalocele / Gastroschisis	nr	0.00*	0.00	0.00	0.00	0.00	0.00
Prune belly sequence	nr	nr	nr	nr	0.11*	0.00	0.06
Trisomy 13	nr	0.14*	0.23	0.22	0.14	0.45	0.88
Trisomy 18	nr	0.22*	0.25	0.34	0.27	1.19	2.09
Down syndrome, all ages (include age unknown)	8.99	8.92	7.53	8.38	7.33	11.87	14.96
<20	nr	1.06*	1.82	2.19	1.40	3.82	8.81
20-24	nr	0.97*	2.47	2.85	1.97	5.55	7.47
25-29	nr	3.93*	3.52	3.85	2.27	7.66	7.45
30-34	nr	6.30*	5.02	4.98	3.97	10.88	13.46
35-39	nr	6.75*	12.28	20.09	15.55	36.01	42.43
40+	nr	113.51*	45.49	58.69	82.04	157.56	149.62
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

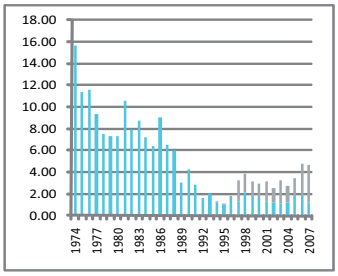
Hungary

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

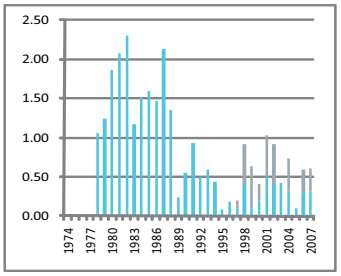
Anencephaly



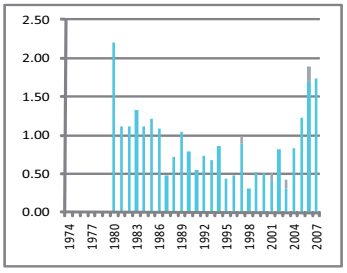
Spina Bifida



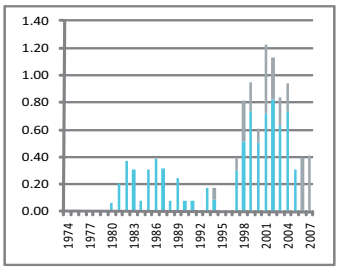
Encephalocele



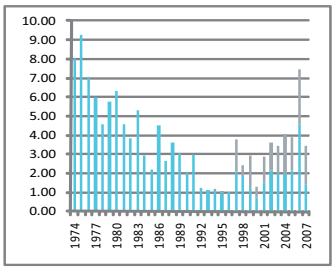
Microcephaly



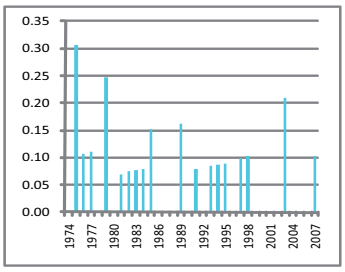
Holoprosencephaly



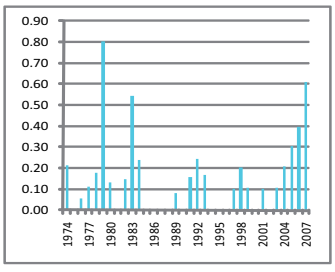
Hydrocephaly



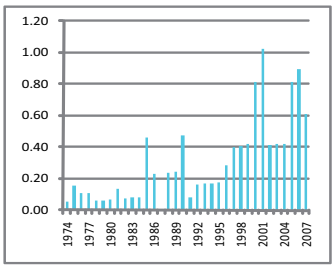
Anophthalmos



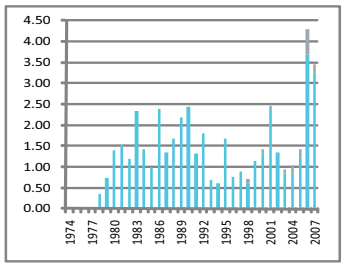
Microphthalmos



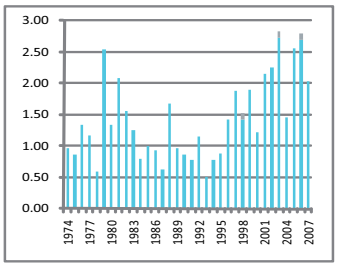
Anotia



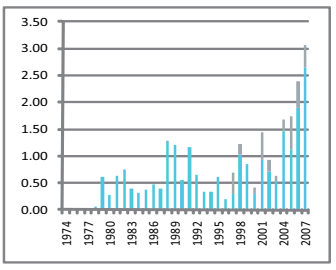
Transposition of great vessels



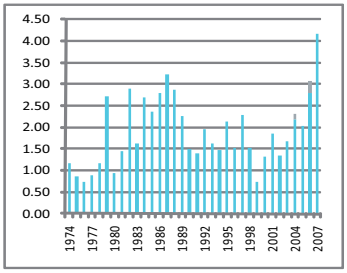
Tetralogy of Fallot



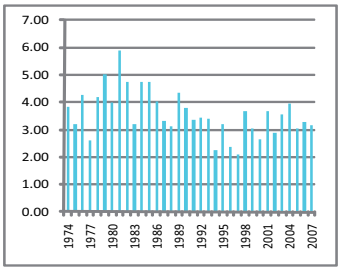
Hypoplastic left heart syndrome



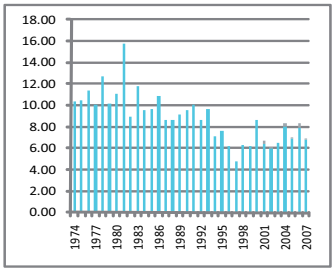
Coarctation of aorta



Cleft palate without cleft lip



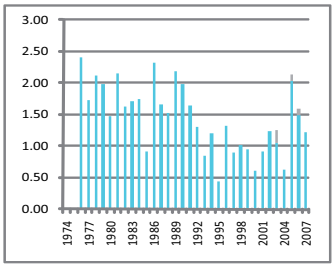
Cleft lip with or without cleft palate



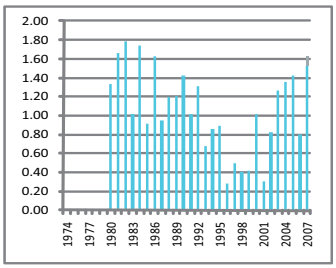
Note: L+S rates, ToP rates

Hungary

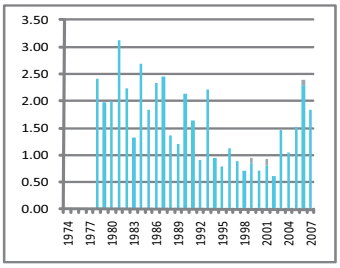
Oesophageal atresia/stenosis with or without fistula



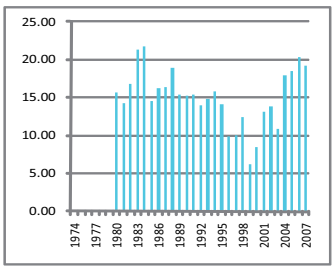
Small intestine atresia/stenosis



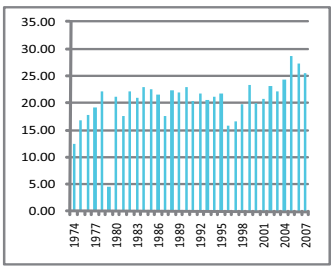
Anorectal atresia/stenosis



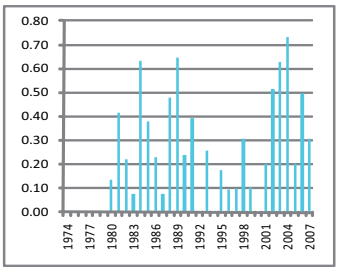
Undescended testis



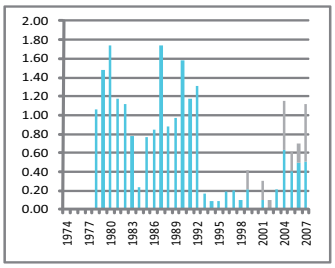
Hypospadias



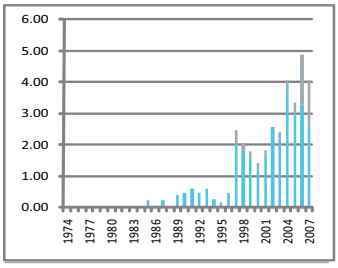
Indeterminate sex



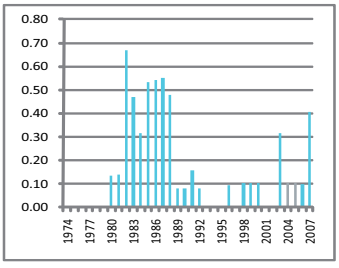
Renal agenesis



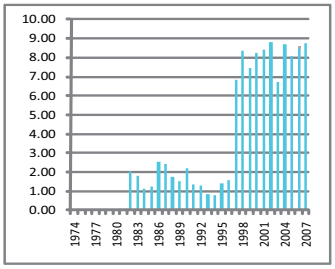
Cystic kidney



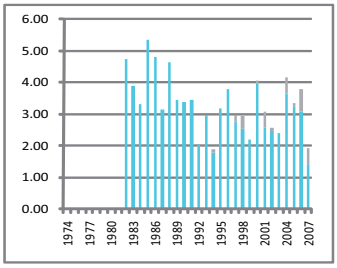
Bladder exstrophy



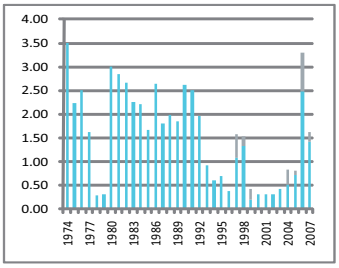
Limb reduction defects



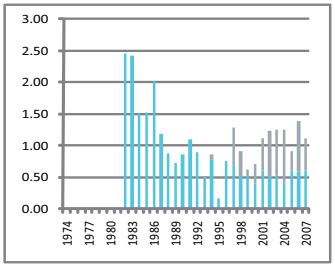
Limb reduction defects



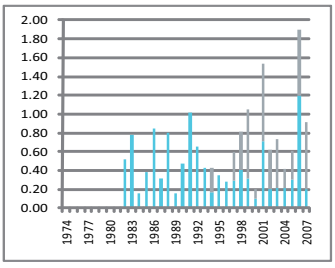
Diaphragmatic hernia



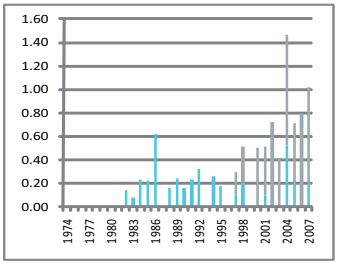
Omphalocele



Gastroschisis



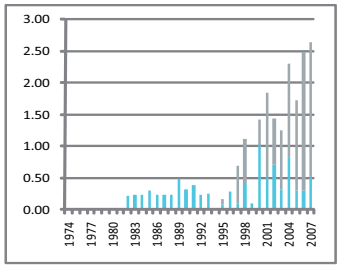
Trisomy 13



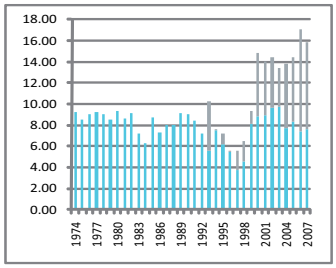
Note: L+S rates, ToP rates

Hungary

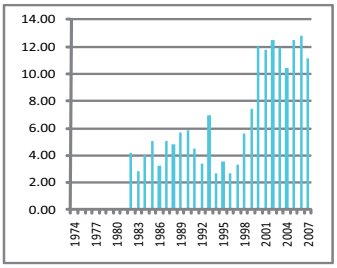
Trisomy 13



Down Syndrome



Down Syndrome standardized total rate



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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Tabriz, Iran
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Fax: 98-411 336 4668
E-mail: saeed.dastgiri@gmail.com
Website: http://www.tbzmed.ac.ir/troca

Iran:TROCA, 2007

Live births (LB)	21,055
Stillbirths (SB)	214
Total births	21,269
Number of terminations of pregnancy (ToP) for birth defects	41

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	16	13	31	28.21
Spina bifida	2	1	nr	1.41
Encephalocele	nr	nr	nr	nr
Microcephaly	9	3	nr	5.64
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	26	13	8	22.10
Anophthalmos	nr	nr	nr	nr
Microphthalmos	2	nr	nr	0.94
Unspecified Anophthalmos/Microphthalmos	4	1	nr	2.35
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	18	nr	nr	8.46
Tetralogy of Fallot	nr	nr	nr	nr
Hypoplastic left heart syndrome	nr	nr	nr	nr
Coarctation of aorta	nr	nr	nr	nr
Choanal atresia, bilateral	nr	nr	nr	nr
Cleft palate without cleft lip	9	nr	nr	4.23
Cleft lip with or without cleft palate	13	nr	nr	6.11
Oesophageal atresia/stenosis with or without fistula	48	nr	nr	22.57
Small intestine atresia/stenosis	nr	nr	nr	nr
Anorectal atresia/stenosis	20	nr	nr	9.40
Undescended testis (36 weeks of gestation or later)	16	nr	nr	7.52
Hypospadias	30	nr	nr	14.11
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	2	nr	nr	0.94
Cystic kidney	3	nr	1	1.41
Bladder exstrophy	nr	nr	nr	nr
Polydactyly, preaxial	9	nr	nr	4.23
Total Limb reduction defects (include unspecified)	55	4	1	28.21
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	16	nr	nr	7.52
Omphalocele	2	nr	nr	0.94
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	nr	nr	nr	nr
Trisomy 18	3	nr	nr	1.41
Down syndrome, all ages (include age unknown)	27	nr	nr	12.69
<20	4	nr	nr	11.11
20-24	8	nr	nr	12.42
25-29	3	nr	nr	5.14
30-34	2	nr	nr	5.69
35-39	4	nr	nr	27.91
40-44	1	nr	nr	27.47
45+	1	nr	nr	147.06
unknown	4	nr	nr	---

nr = not reported

Ireland
Dublin EUROCAT Registry

History:
Register began in September 1979 and joined EUROCAT at the same time. Joined ICBDSR 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 (22,000 births) of all births in Ireland occur in this region.

Legislation and funding:
The Registry is located within the Population Health Directorate of the Health Service Executive. Staffing includes a full time Research Nurse and a part time secretary and is led by a Specialist in Public Health Medicine. Funding is provided by the Department of Health through the Health Service Executive. There is a Steering Committee comprised of specialists from each of Maternity and Paediatric Hospitals in the catchment plus a representative from the Department of Health.

Exposure information:
For each malformed infant reported, very 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.

Addresses and Staff:
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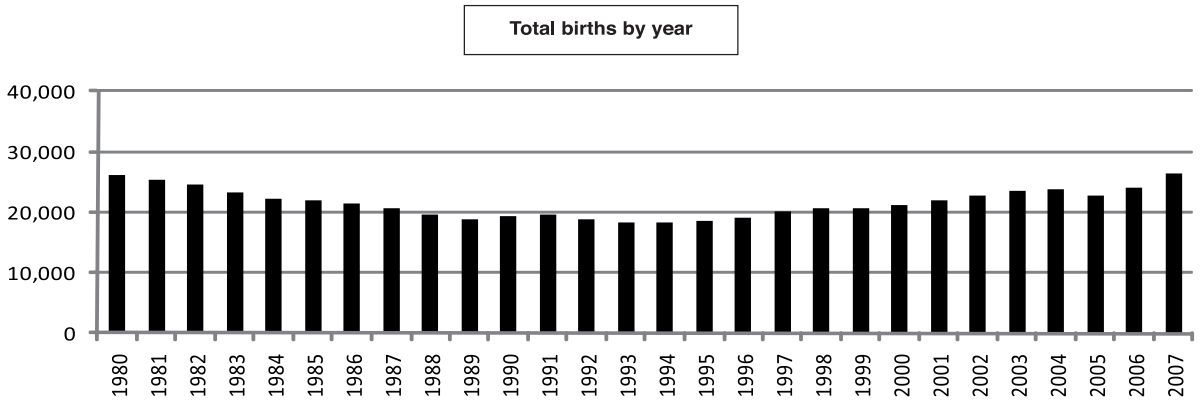
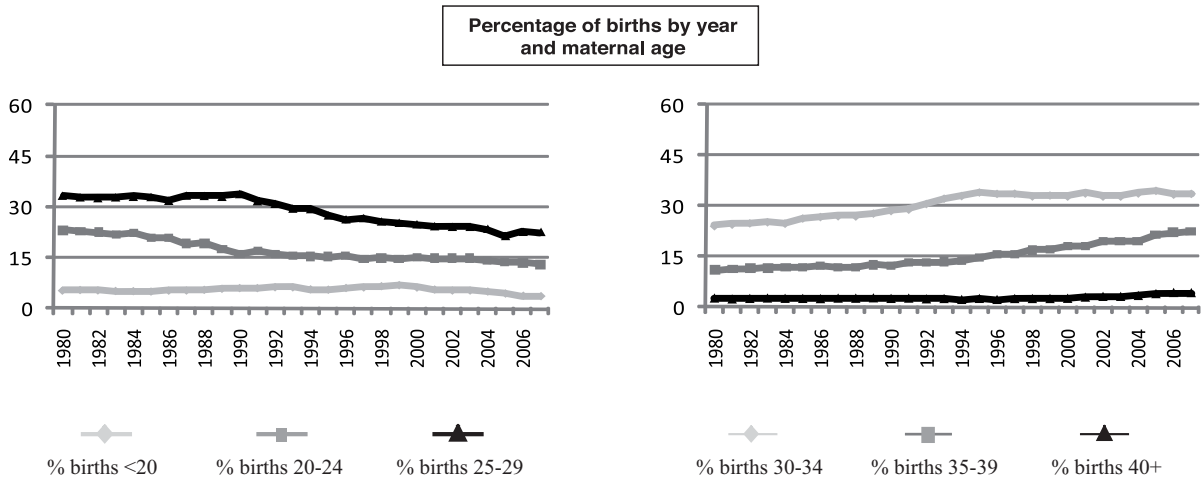
Dublin 8 - Ireland
Phone: 353-1-6352752
353-1-6353745
E-mail: bob.mcdonnell@hse.ie

Virginia Delany, Registry Co-ordinator/Research nurse
Phone: 353-1-6352751
Fax: 353-1-6353745
E-mail: virginia.delaney@hse.ie

Ireland: Dublin





Ireland: Dublin, 2007

Live births (LB)	26,250
Stillbirths (SB)	120
Total births	26,370
Number of terminations of pregnancy (ToP) for birth defects	not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	2		1.90
Spina bifida	8	1		3.41
Encephalocele	4	0		1.52
Microcephaly	4	0		1.52
Holoprosencephaly	4	1		1.90
Hydrocephaly	3	1		1.52
Anophthalmos	2	0		0.76
Microphthalmos	2	0		0.76
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	1	0		0.38
Microtia	0	0		0.00
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	11	1		4.55
Tetralogy of Fallot	8	1		3.41
Hypoplastic left heart syndrome	7	2		3.41
Coarctation of aorta	11	1		4.55
Choanal atresia, bilateral	2	0		0.76
Cleft palate without cleft lip	19	0		7.21
Cleft lip with or without cleft palate	23	2		9.48
Oesophageal atresia/stenosis with or without fistula	5	2		2.65
Small intestine atresia/stenosis	3	1		1.52
Anorectal atresia/stenosis	9	0		3.41
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	26	1		10.24
Epispadias	nr	nr		nr
Indeterminate sex	0	0		0.00
Renal agenesis	3	1		1.52
Cystic kidney	10	0		3.79
Bladder exstrophy	1	0		0.38
Polydactyly, preaxial	18	0		6.83
Total Limb reduction defects (include unspecified)	4	5		3.41
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	4	5		3.41
Diaphragmatic hernia	8	1		3.41
Omphalocele	4	1		1.90
Gastroschisis	7	0		2.65
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	2	0		0.76
Trisomy 13	5	3		3.03
Trisomy 18	5	8		4.93
Down syndrome, all ages (include age unknown)	66	8		28.06
<20	0	0		0.00
20-24	3	1		11.72
25-29	6	1		11.83
30-34	23	1		27.03
35-39	25	5		50.56
40-44	9	0		83.49
45+	0	0		0.00
unknown	0	0		0.00

nr = not reported

Ireland: Dublin, Previous years rates 1980 - 2007

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

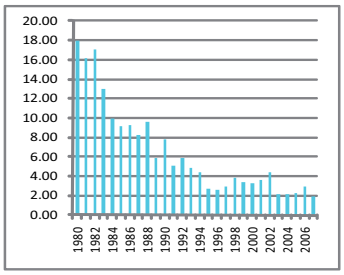
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births		**76,132**	**109,399**	**96,278**	**94,462**	**107,313**	**120,532**
Anencephaly		17.08	9.96	6.86	3.49	3.73	2.24
Spina bifida		12.74	14.53	7.48	5.50	4.75	3.15
Encephalocele		3.28	1.46	2.29	1.59	1.49	1.08
Microcephaly		3.55	3.93	2.80	5.08	3.91	3.48
Holoprosencephaly		0.00	0.46	0.42	0.95	1.40	1.41
Hydrocephaly		nr	nr	nr	2.29*	2.42	2.07
Anophthalmos		0.39	0.09	0.00	0.74	0.28	0.41
Microphthalmos		0.26	1.01	1.45	2.01	1.96	0.91
Unspecified Anophthalmos / Microphthalmos		nr	nr	nr	nr	0.19	0.00
Anotia		nr	nr	nr	nr	nr	0.17
Microtia		nr	nr	nr	nr	nr	0.17
Unspecified Anotia / Microtia		nr	nr	nr	nr	nr	0.00
Transposition of great vessels		nr	nr	nr	6.61*	4.29	3.65
Tetralogy of Fallot		2.76	2.74	2.80	3.39	3.26	3.07
Hypoplastic left heart syndrome		2.10	2.38	1.97	1.91	2.33	3.40
Coarctation of aorta		4.20	6.58	5.19	6.35	5.59	6.97
Choanal atresia, bilateral		0.53	0.46	0.62	1.59	1.68	0.83
Cleft palate without cleft lip		7.22	7.13	7.58	8.36	8.20	7.80
Cleft lip with or without cleft palate		10.38	8.59	8.21	9.21	8.48	7.38
Oesophageal atresia / stenosis with or without fistula		4.33	3.11	3.74	3.07	2.80	2.49
Small intestine atresia / stenosis		2.10	3.11	2.08	2.65	1.77	1.24
Anorectal atresia / stenosis		3.55	3.66	3.12	2.96	2.14	3.24
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr
Hypospadias		12.08	13.44	13.81	13.23	18.26	11.28
Epispadias		nr	nr	nr	nr	nr	nr
Indeterminate sex		0.13	0.18	0.21	0.32	0.19	0.33
Renal agenesis		4.07	6.12	3.53	3.81	3.45	1.83
Cystic kidney		2.50	3.56	1.45	6.25	2.42	4.65
Bladder exstrophy		nr	nr	nr	1.27*	0.37	1.00
Polydactyly, preaxial		5.65	7.04	5.19	5.72	9.60	8.55
‘Total Limb reduction defects (include unspecified)		4.33	3.47	4.05	4.34	4.75	3.90
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		nr	nr	nr	nr	5.71*	4.19*
Diaphragmatic hernia		3.28	3.38	4.57	4.23	4.75	2.90
Omphalocele		2.89	1.92	2.18	2.96	3.17	3.15
Gastroschisis		0.13	0.46	0.62	1.59	2.70	3.24
Unspecified Omphalocele / Gastroschisis		nr	nr	nr	nr	nr	nr
Prune belly sequence		0.13	0.09	0.42	0.74	0.28	0.83
Trisomy 13		1.18	0.91	1.14	1.38	3.45	2.07
Trisomy 18		2.50	1.92	2.18	4.02	3.91	4.31
Down syndrome, all ages (include age unknown)		19.18	18.83	18.28	22.02	22.83	22.82
<20		nr	nr	16.68*	14.02	4.52	13.01
20-24		nr	nr	9.96*	7.65	8.16	7.83
25-29		nr	nr	10.30*	9.13	8.65	7.32
30-34		nr	nr	8.64*	19.30	16.84	17.28
35-39		nr	nr	40.39*	45.92	49.83	46.54
40-44		nr	nr	237.58*	147.25	154.62	102.66
45+		nr	nr	1666.67*	618.56	412.37	60.98
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

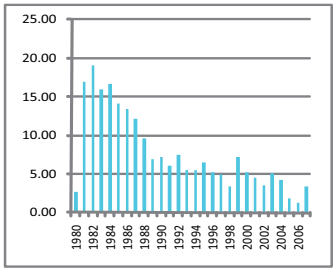
Ireland: Dublin

Time trends 1980-2007 (Birth prevalence rates per 10,000)

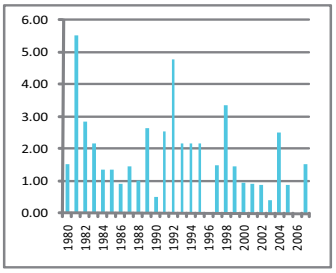
Anencephaly



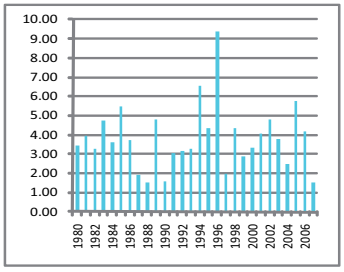
Spina Bifida



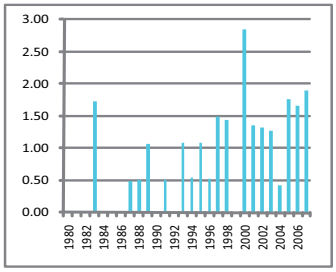
Encephalocele



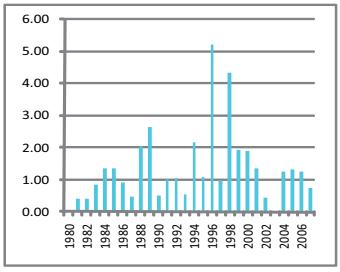
Microcephaly



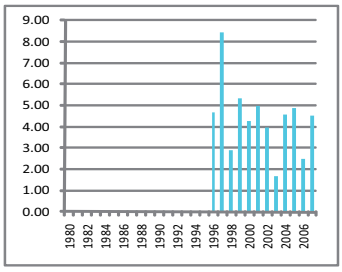
Holoprosencephaly



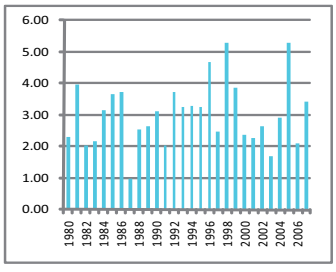
Microphthalmos



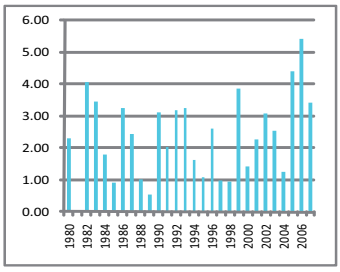
Transposition of great vessels



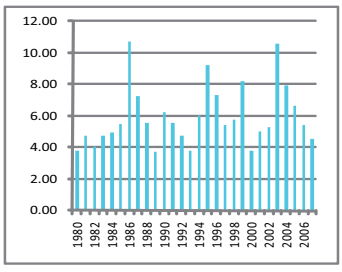
Tetralogy of Fallot



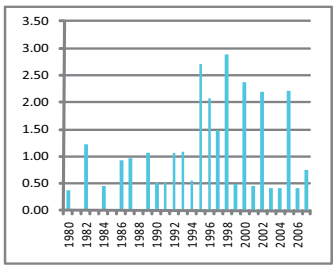
Hypoplastic left heart syndrome



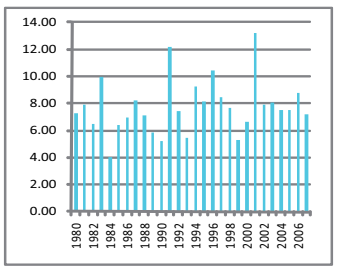
Coarctation of aorta



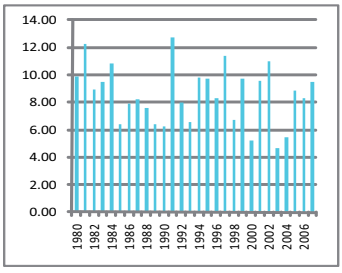
Choanal atresia, bilateral



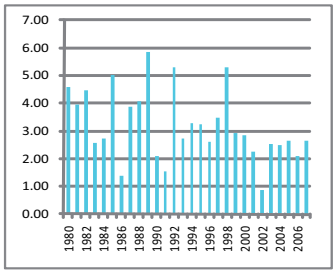
Cleft palate without cleft lip



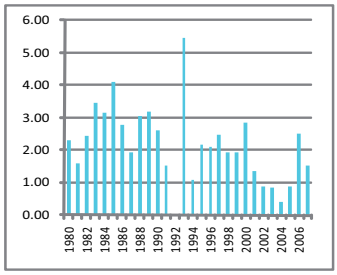
Cleft lip with or without cleft palate



Oesophageal atresia/stenosis with or without fistula



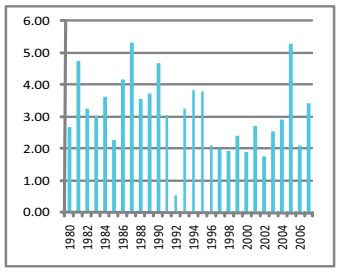
Small intestine atresia/stenosis



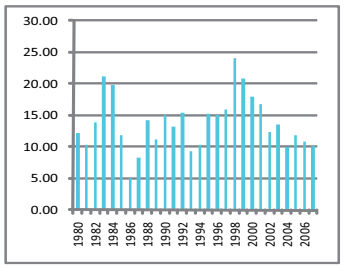
Note: L+S rates

Ireland: Dublin

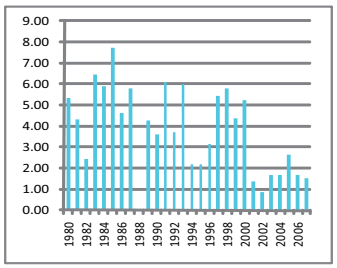
Anorectal atresia/stenosis



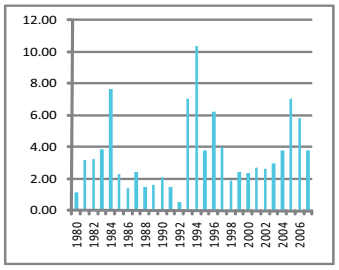
Hypospadias



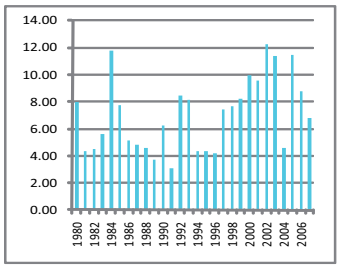
Renal agenesis



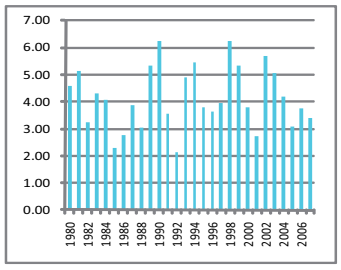
Cystic kidney



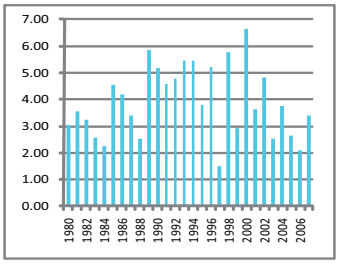
Polydactyly, preaxial



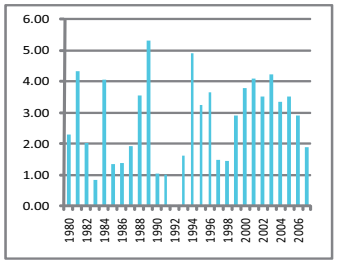
Limb reduction defects



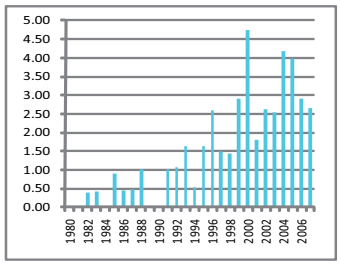
Diaphragmatic hernia



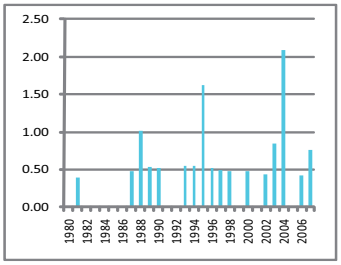
Omphalocele



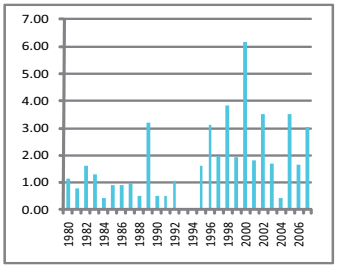
Gastroschisis



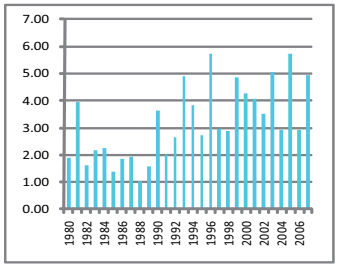
Prune belly sequence



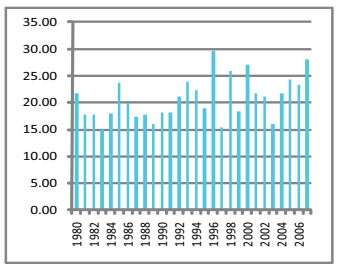
Trisomy 13



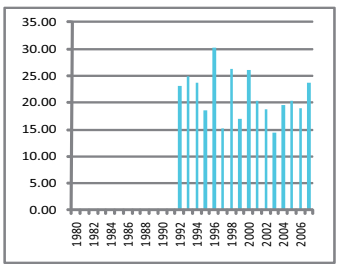
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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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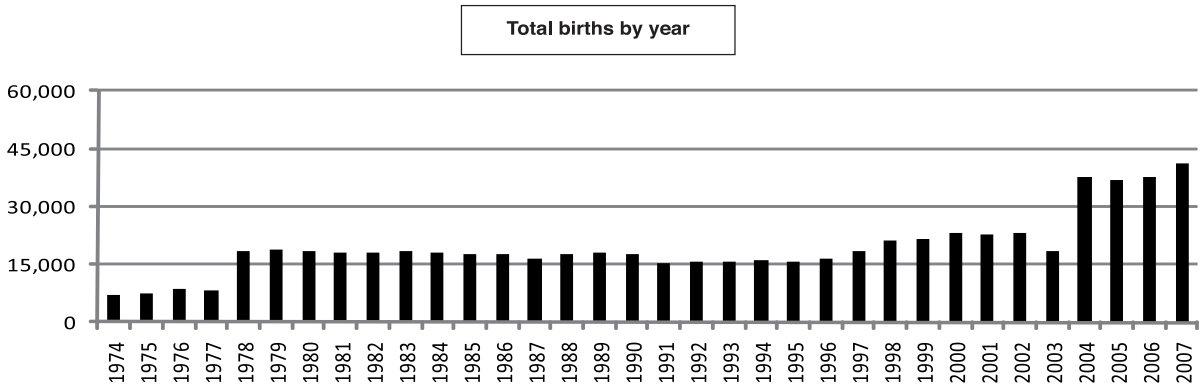
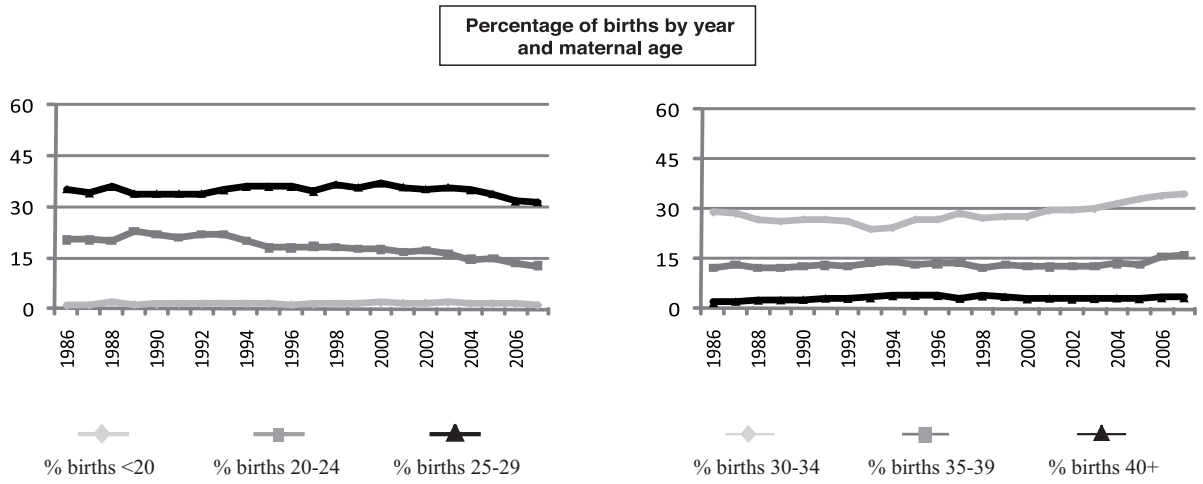
Israel: IBDSP





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	1	7.1	Cystic kidney	0	0.0
Spina bifida	9	32.1	Limb reduction defects	2	8.3
Encephalocele	0	0.0	Diaphragmatic hernia	0	0.0
Holoprosencephaly	1	20.0	Omphalocele	2	15.4
Hydrocephaly	10	21.3	Gastroschisis	0	0.0
Hypoplastic left heart syndrome	4	16.7	Trisomy 13	1	33.3
Cleft palate without cleft lip	0	0.0	Trisomy 18	0	0.0
Cleft lip with or without cleft palate	4	8.2	Down syndrome	20	22.7
Renal agenesis	1	6.7			

Total ToPs with births defects = 68 (Ratio ToPs/Births: 0.59 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Israel: IBDSP, 2007

Live births (LB)	40,690
Stillbirths (SB)	335
Total births	41,025
Number of terminations of pregnancy (ToP) for birth defects	18

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	1	0	0.73
Spina bifida	3	1	3	1.71
Encephalocele	2	0	0	0.49
Microcephaly	7	0	0	1.71
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	10	1	7	4.39
Anophthalmos	0	0	0	0.00
Microphthalmos	3	0	0	0.73
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	2	0	0	0.49
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	12	1	0	3.17
Tetralogy of Fallot	13	0	0	3.17
Hypoplastic left heart syndrome	6	0	0	1.46
Coarctation of aorta	16	0	0	3.90
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	12	0	0	2.93
Cleft lip with or without cleft palate	13	1	1	3.66
Oesophageal atresia/stenosis with or without fistula	15	0	0	3.66
Small intestine atresia/stenosis	2	0	0	0.49
Anorectal atresia/stenosis	14	0	0	3.41
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	145	0	0	35.34
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	0.24
Renal agenesis	2	0	1	0.73
Cystic kidney	3	0	0	0.73
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	2	0	0	0.49
Total Limb reduction defects (include unspecified)	6	0	1	1.71
Transverse	4	0	0	0.98
Preaxial	0	0	0	0.00
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.24
Mixed	1	0	1	0.49
Unspecified	0	0	0	0.00
Diaphragmatic hernia	8	1	0	2.19
Omphalocele	3	0	0	0.73
Gastroschisis	3	0	0	0.73
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	2	0	0	0.49
Down syndrome, all ages (include age unknown)	18	0	5	5.61
<20	0	0	0	0.00
20-24	2	0	0	3.82
25-29	1	0	1	1.55
30-34	1	0	1	1.40
35-39	6	0	1	10.43
40-44	7	0	2	70.75
45+	1	0	0	76.34
unknown	0	0	0	---

nr = not reported

Israel: IBDSP, Previous years rates 1974 - 2007

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

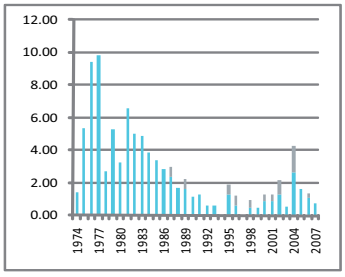
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**31,113**	**91,966**	**88,516**	**84,404**	**82,573**	**112,083**	**171,830**
Anencephaly	6.75	4.57	3.62	1.42	0.73	1.25	1.80
Spina bifida	3.86	3.81	6.67	2.49	2.18	3.30	2.85
Encephalocele	0.32	0.33	0.34	1.07	0.61	0.27	0.41
Microcephaly	nr	nr	0.00*	0.00	0.00	1.70	2.15
Holoprosencephaly	nr	nr	0.14*	0.36	0.24	0.00	0.35
Hydrocephaly	4.50	3.48	3.16	3.08	4.72	6.16	4.83
Anophthalmos	0.00	0.00	0.00	0.00	0.00	0.18	0.00
Microphthalmos	1.61	0.22	0.11	0.71	0.48	0.98	0.47
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	0.12	0.00	0.00
Microtia	0.32	0.87	1.24	1.90	2.30	0.71	0.87
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	nr	nr	2.33*	3.79	3.03	4.37	3.72
Tetralogy of Fallot	nr	0.91*	1.47	3.55	3.27	3.12	4.54
Hypoplastic left heart syndrome	nr	nr	1.46*	2.25	3.03	1.87	2.10
Coarctation of aorta	nr	0.18*	0.45	2.49	2.42	2.86	3.26
Choanal atresia, bilateral	nr	nr	0.28*	0.24	0.12	0.27	0.06
Cleft palate without cleft lip	5.14	3.81	5.42	4.50	5.45	4.37	3.38
Cleft lip with or without cleft palate	5.46	4.35	5.87	6.04	3.51	5.80	4.36
Oesophageal atresia / stenosis with or without fistula	1.61	1.63	1.81	3.91	3.39	1.61	3.08
Small intestine atresia / stenosis	nr	nr	1.28*	1.18	1.09	0.45	0.87
Anorectal atresia / stenosis	0.96	2.61	3.73	3.91	3.27	1.34	2.10
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	36.00	25.01	30.05	38.74	36.57	38.36	32.36
Epispadias	0.32	0.00	0.11	0.24	0.00	0.27	0.12
Indeterminate sex	nr	nr	0.00*	0.00	0.00	0.00	0.25
Renal agenesis	nr	nr	0.87*	0.83	0.36	0.45	1.34
Cystic kidney	0.96	0.54	1.02	1.30	0.73	2.32	1.57
Bladder exstrophy	0.00	0.22	0.68	0.47	0.24	0.18	0.41
Polydactyly, preaxial	0.32	0.65	0.23	0.36	0.97	0.98	0.76
'Total Limb reduction defects (include unspecified)	3.86	2.83	3.05	2.96	2.42	1.25	2.50
Transverse	nr	0.00*	0.90	1.78	0.73	0.54	1.28
Preaxial	nr	0.00*	0.79	0.36	0.61	0.45	0.70
Postaxial	nr	1.11*	0.23	0.24	0.48	0.09	0.06
Intercalary	nr	0.00*	0.45	0.24	0.12	0.18	0.29
Mixed	nr	0.55*	0.68	0.36	0.48	0.00	0.17
Unspecified	nr	0.00*	0.00	0.00	0.00	0.00	0.00
Diaphragmatic hernia	nr	2.28	2.26	2.61	1.70	1.78	1.92
Omphalocele	2.25	1.85	1.92	1.07	0.48	0.71	1.05
Gastroschisis	nr	0.11	0.90	0.00	0.12	0.27	0.35
Unspecified Omphalocele / Gastroschisis	nr	0.00	0.00	0.00	0.12	0.09	0.00
Prune belly sequence	0.64	0.22	0.11	0.12	0.00	0.18	0.17
Trisomy 13	nr	nr	0.42*	0.59	0.24	0.54	0.35
Trisomy 18	nr	nr	0.71*	0.59	0.97	1.07	0.99
Down syndrome, all ages (include age unknown)	12.86	8.92	12.99	9.48	7.39	9.28	8.61
<20	nr	nr	nr	0.00*	0.00	5.03	11.04
20-24	nr	nr	nr	0.00*	1.26	2.57	4.53
25-29	nr	nr	nr	3.76*	4.10	4.95	3.84
30-34	nr	nr	nr	7.19*	6.92	7.85	5.09
35-39	nr	nr	nr	22.23*	13.21	20.21	16.40
40-44	nr	nr	nr	51.75*	43.59	57.77	76.47
45+	nr	nr	nr	0.00*	117.99	120.12	51.28
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

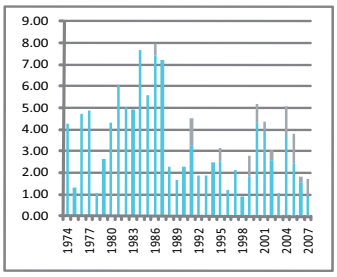
Israel: IBDSP

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

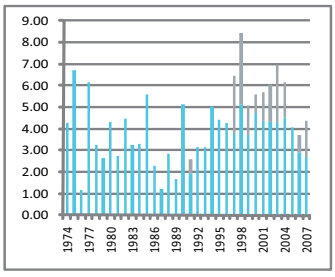
Anencephaly



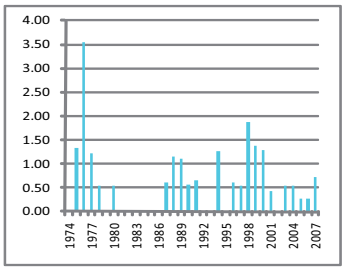
Spina Bifida



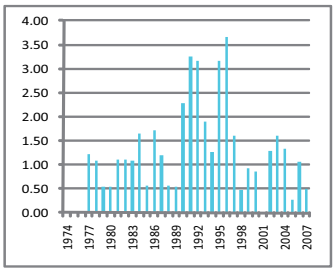
Encephalocele



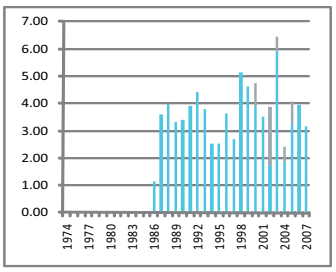
Microphthalmos



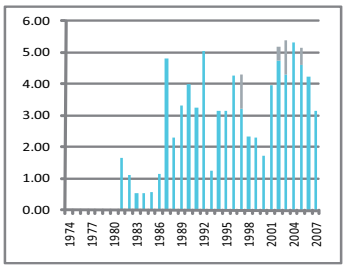
Microtia



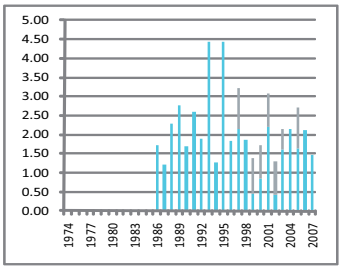
Transposition of great vessels



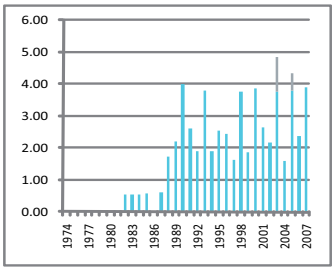
Tetralogy of Fallot



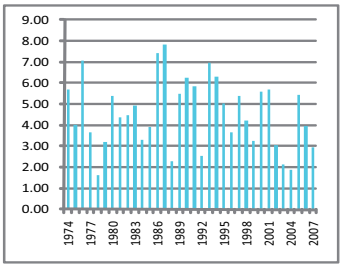
Hypoplastic left heart syndrome



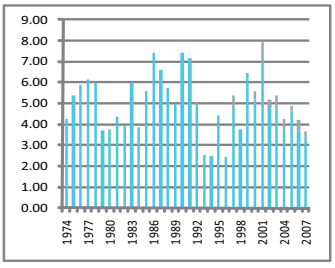
Coarctation of aorta



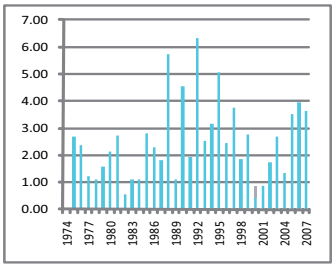
Cleft palate without cleft lip



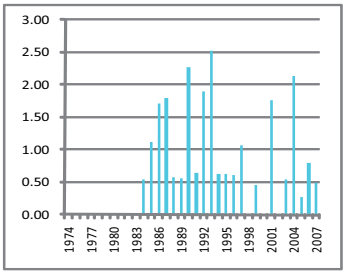
Cleft lip with or without cleft palate



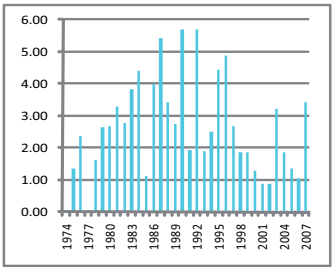
Oesophageal atresia/stenosis with or without fistula



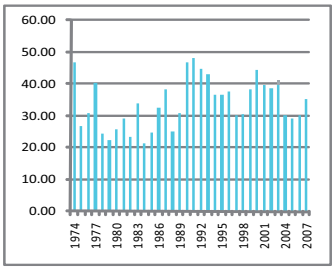
Small intestine atresia/stenosis



Anorectal atresia/stenosis



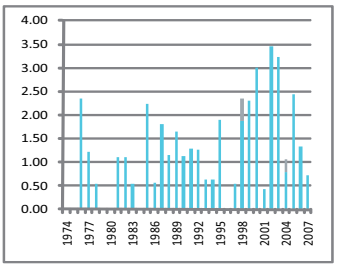
Hypospadias



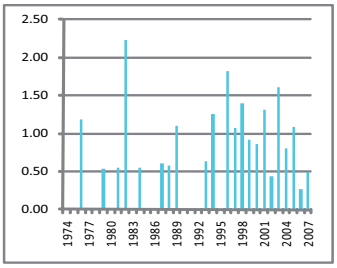
Note: L+S rates, ToP rates

Israel: IBDSP

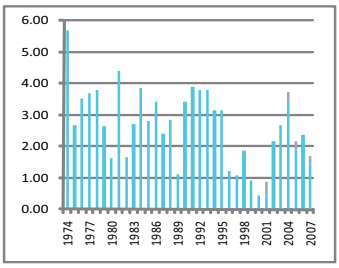
Cystic kidney



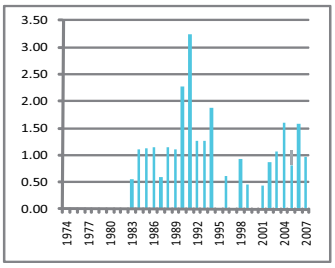
Polydactyly, preaxial



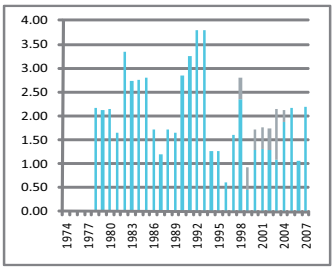
Limb reduction defects



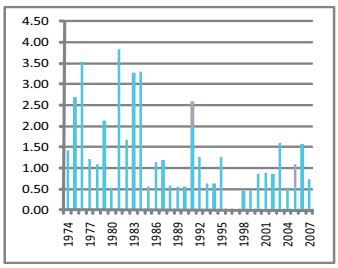
Limb reduction defects - transverse



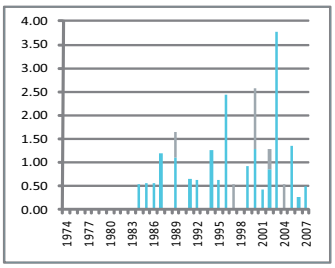
Diaphragmatic hernia



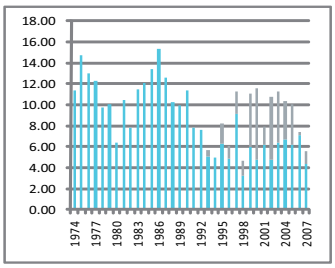
Omphalocele



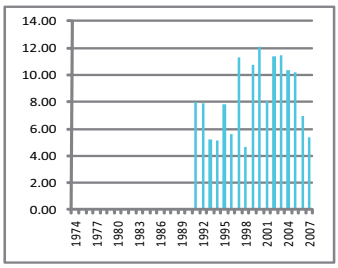
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Italy - Campania: BDRCam
Birth Defects Registry of Campania

History:
The Registry started in 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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Phone: 39- 0824-57374
Fax: 39-0824-57495
E-mail: giorecam@tin.it

Italy: BDRCam, 2007

Live births (LB)	55,956
Stillbirths (SB)	104
Total births	56,060
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	0	11	1.96
Spina bifida	3	0	8	1.96
Encephalocele	0	0	4	0.71
Microcephaly	2	0	0	0.36
Holoprosencephaly	0	0	3	0.54
Hydrocephaly	2	0	22	4.28
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	6	0	0	1.07
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	0	0	0	0.00
Tetralogy of Fallot	5	0	2	1.25
Hypoplastic left heart syndrome	0	0	5	0.89
Coarctation of aorta	4	0	0	0.71
Choanal atresia, bilateral	2	0	0	0.36
Cleft palate without cleft lip	10	0	0	1.78
Cleft lip with or without cleft palate	18	0	3	3.75
Oesophageal atresia/stenosis with or without fistula	6	0	0	1.07
Small intestine atresia/stenosis	2	0	0	0.36
Anorectal atresia/stenosis	2	0	1	0.54
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	4	0	0	0.71
Epispadias	2	0	0	0.36
Indeterminate sex	1	0	0	0.18
Renal agenesis	15	0	8	4.10
Cystic kidney	4	0	2	1.07
Bladder exstrophy	1	0	1	0.36
Polydactyly, preaxial	5	0	0	0.89
Total Limb reduction defects (include unspecified)	0	0	0	0.00
Transverse	7	0	1	1.43
Preaxial	1	0	2	0.54
Postaxial	1	0	0	0.18
Intercalary	0	0	0	0.00
Mixed	1	0	0	0.18
Unspecified	0	0	0	0.00
Diaphragmatic hernia	4	0	1	0.89
Omphalocele	2	0	1	0.54
Gastroschisis	1	0	3	0.71
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	0	0	1	0.18
Trisomy 18	0	0	6	1.07
Down syndrome, all ages (include age unknown)	24	0	55	14.09
<20	0	0	0	0.00
20-24	1	0	0	0.94
25-29	2	0	4	5.02
30-34	4	0	5	4.74
35-39	6	0	17	22.92
40-44	7	0	17	115.72
45+	0	0	3	76.34
unknown	4	0	9	---

nr = not reported

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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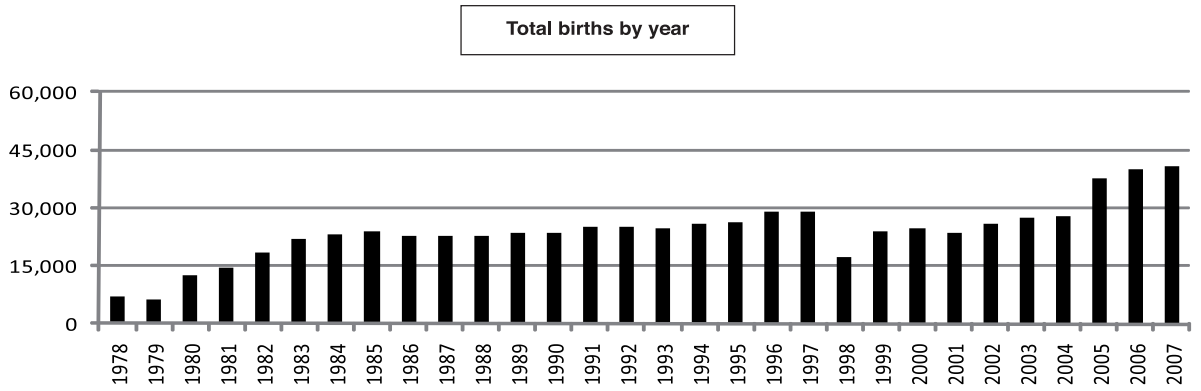
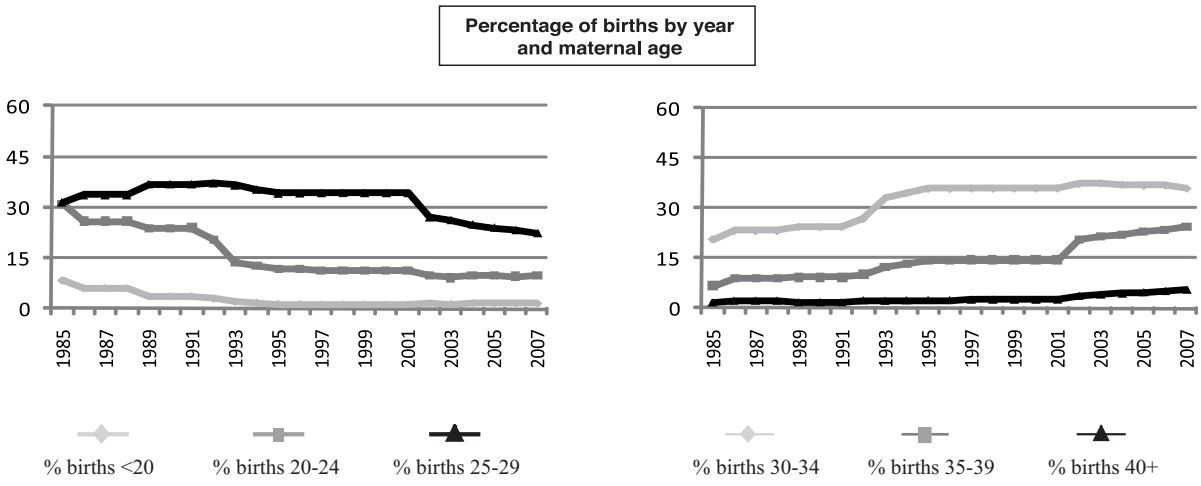
40138 Bologna, Italy

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 (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	18	75.0	Cystic kidney	24	45.3
Spina bifida	21	70.0	Limb reduction defects	12	18.8
Encephalocele	6	75.0	Diaphragmatic hernia	3	11.1
Holoprosencephaly	15	88.2	Omphalocele	10	58.8
Hydrocephaly	43	72.9	Gastroschisis	4	36.4
Hypoplastic left heart syndrome	20	54.1	Trisomy 13	15	88.2
Cleft palate without cleft lip	4	7.0	Trisomy 18	44	88.0
Cleft lip with or without cleft palate	16	20.8	Down syndrome	144	65.5
Renal agenesis	20	39.2			

Total ToPs with births defects = 567 (Ratio ToPs/Births: 4.80 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: IMER, 2007

Live births (LB)	40,548
Stillbirths (SB)	114
Total births	40,662
Number of terminations of pregnancy (ToP) for birth defects	195

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	1	2	5	1.97
Spina bifida	2	0	6	1.97
Encephalocele	0	0	3	0.74
Microcephaly	5	0	2	1.72
Holoprosencephaly	1	0	7	1.97
Hydrocephaly	2	0	14	3.93
Anophthalmos	0	0	0	0.00
Microphthalmos	3	0	1	0.98
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	4	0	0	0.98
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	18	0	1	4.67
Tetralogy of Fallot	12	0	1	3.20
Hypoplastic left heart syndrome	6	0	6	2.95
Coarctation of aorta	8	0	3	2.71
Choanal atresia, bilateral	1	0	0	0.25
Cleft palate without cleft lip	23	0	4	6.64
Cleft lip with or without cleft palate	20	0	4	5.90
Oesophageal atresia/stenosis with or without fistula	9	0	0	2.21
Small intestine atresia/stenosis	8	0	0	1.97
Anorectal atresia/stenosis	6	0	0	1.48
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	62	0	2	15.74
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	0.25
Renal agenesis	14	0	8	5.41
Cystic kidney	9	0	11	4.92
Bladder exstrophy	1	0	0	0.25
Polydactyly, preaxial	17	0	1	4.43
Total Limb reduction defects (include unspecified)	12	1	5	4.43
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	6	1	1	1.97
Omphalocele	3	0	5	1.97
Gastroschisis	1	0	2	0.74
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	9	2.46
Trisomy 18	2	0	10	2.95
Down syndrome, all ages (include age unknown)	25	0	54	19.43
<20	1	0	0	16.89
20-24	1	0	0	2.50
25-29	4	0	4	8.90
30-34	4	0	9	8.94
35-39	10	0	26	36.39
40-44	4	0	14	83.68
45+	0	0	1	97.09
unknown	1	0	0	---

nr = not reported

Italy: IMER, Previous years rates 1978 - 2007

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

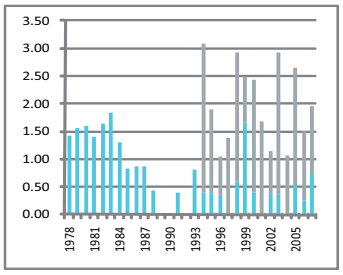
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births		**58,562**	**114,547**	**119,890**	**134,517**	**115,482**	**173,488**
Anencephaly		1.54	1.13	0.17	1.64	2.08	2.02
Spina bifida		3.93	4.19	4.09	2.90	3.72	3.52
Encephalocele		0.51	0.70	0.67	0.67	0.61	0.75
Microcephaly		1.54	2.44	2.09	1.12	1.21	1.50
Holoprosencephaly		0.00	0.35	0.42	0.74	1.13	1.50
Hydrocephaly		3.93	5.06	4.09	3.94	5.46	6.11
Anophthalmos		0.51	0.09	0.17	0.30	0.17	0.23
Microphthalmos		0.17	1.05	0.33	0.97	0.43	1.38
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		nr	nr	nr	0.72*	0.43	1.10
Microtia		nr	nr	nr	0.72*	0.43	0.92
Unspecified Anotia / Microtia		nr	nr	nr	0.00*	0.00	0.00
Transposition of great vessels		2.05	2.88	2.75	2.97	5.02	4.78
Tetralogy of Fallot		0.22*	2.01	1.42	2.01	3.55	3.34
Hypoplastic left heart syndrome		0.68	1.83	1.84	2.08	3.12	2.88
Coarctation of aorta		1.99*	2.71	2.17	2.30	2.42	3.11
Choanal atresia, bilateral		0.00	0.17	0.50	0.07	0.43	0.35
Cleft palate without cleft lip		4.10	5.85	5.92	4.83	4.07	4.61
Cleft lip with or without cleft palate		7.17	7.68	6.09	6.39	5.46	6.57
Oesophageal atresia / stenosis with or without fistula		3.24	3.84	3.59	4.01	2.94	3.40
Small intestine atresia / stenosis		2.39	2.88	3.59	3.42	2.34	2.19
Anorectal atresia / stenosis		2.56	2.97	3.34	2.45	3.03	2.82
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr
Hypospadias		18.27	20.78	19.18	17.25*	15.76	15.10
Epispadias		nr	nr	nr	0.00*	0.00	0.00
Indeterminate sex		nr	nr	nr	0.23*	0.26	0.52
Renal agenesis		2.05	1.40	1.67	1.56	4.24	4.21
Cystic kidney		0.51	0.96	0.25	2.08	3.81	4.55
Bladder exstrophy		0.68	0.61	0.25	0.07	0.35	0.23
Polydactyly, preaxial		10.07	8.03	8.59	4.39	2.51	3.34
‘Total Limb reduction defects (include unspecified)		nr	5.31*	5.92	4.24	3.98	5.65
Transverse		nr	3.01*	3.50	1.86	1.82	1.95*
Preaxial		nr	0.57*	0.75	0.97	0.69	1.35*
Postaxial		nr	0.57*	0.58	0.37	0.52	0.67*
Intercalary		nr	0.43*	0.75	0.37	0.78	0.37*
Mixed		nr	0.28*	0.33	0.30	0.09	0.22*
Unspecified		nr	0.43*	0.00	0.37	0.09	1.43*
Diaphragmatic hernia		1.20	2.01	2.50	2.75	3.46	3.23
Omphalocele		1.37	2.10	1.92	1.56	1.99	2.42
Gastroschisis		0.68	1.05	0.83	0.59	0.78	1.27
Unspecified Omphalocele / Gastroschisis		0.34	0.52	1.08	0.00	0.00	0.00
Prune belly sequence		0.34	0.52	0.25	0.22	0.35	0.06
Trisomy 13		1.88	0.87	0.58	1.04	1.13	1.84
Trisomy 18		0.68	1.05	1.17	1.49	3.64	4.84
Down syndrome, all ages (include age unknown)		16.05	12.13	12.18	18.66	18.79	19.19
<20		nr	2.06*	4.15	9.84	13.67	11.59
20-24		nr	5.72*	4.25	6.68	10.18	4.79
25-29		nr	9.60*	9.64	8.53	5.04	5.57
30-34		nr	14.09*	16.50	11.81	15.23	9.74
35-39		nr	33.60*	23.26	46.33	35.56	37.24
40-44		nr	47.43*	60.27	166.17	132.99	98.96
45+		nr	82.64*	68.49	127.39	256.41	80.00
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

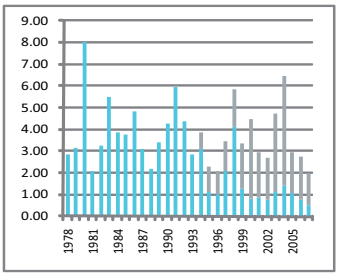
Italy: IMER

Time trends 1978-2007 (Birth prevalence rates per 10,000)

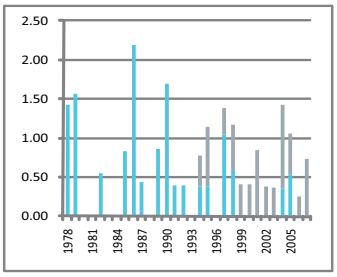
Anencephaly



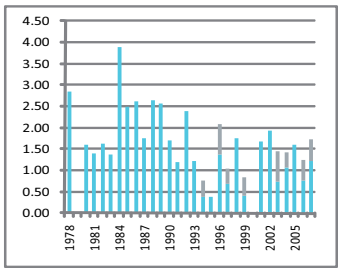
Spina Bifida



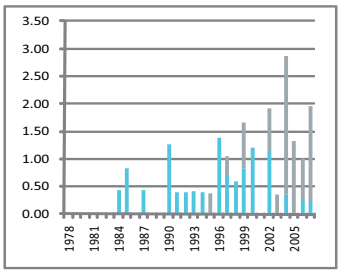
Encephalocele



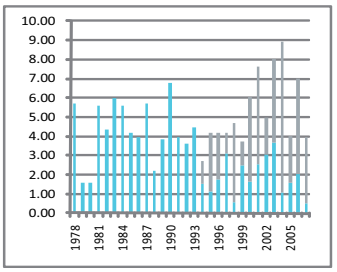
Microcephaly



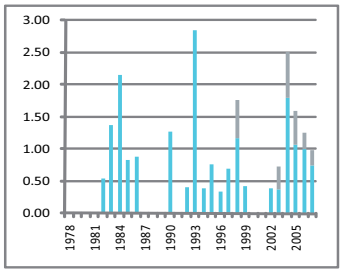
Holoprosencephaly



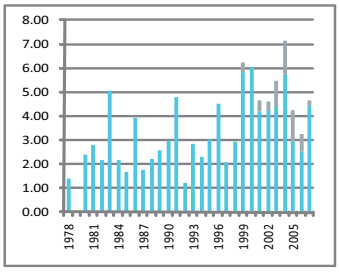
Hydrocephaly



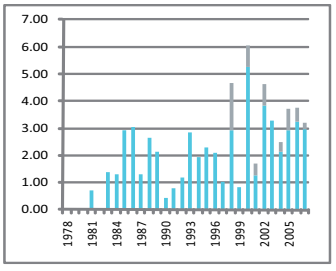
Microphthalmos



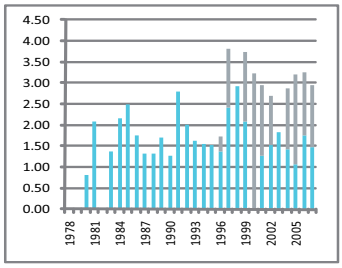
Transposition of great vessels



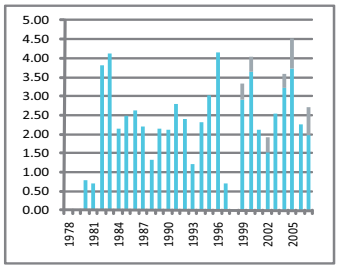
Tetralogy of Fallot



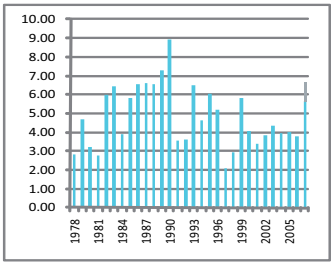
Hypoplastic left heart syndrome



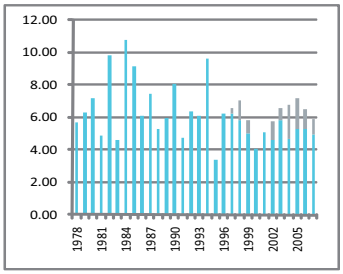
Coarctation of aorta



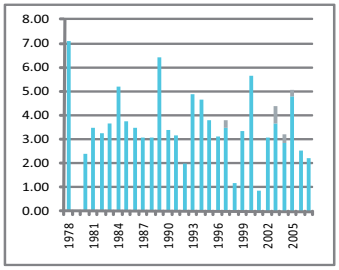
Cleft palate without cleft lip



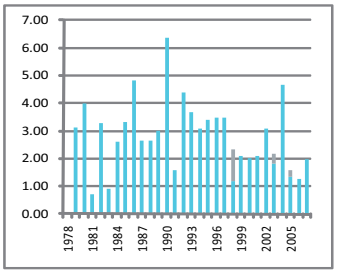
Cleft lip with or without cleft palate



Oesophageal atresia/stenosis with or without fistula



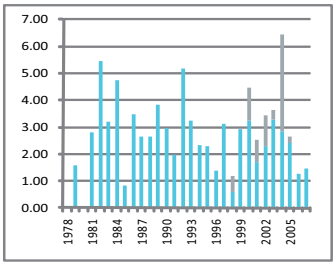
Small intestine atresia/stenosis



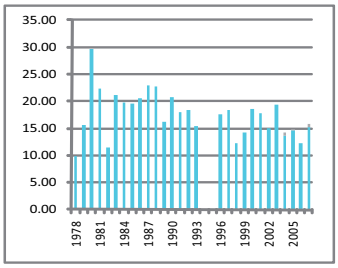
Note: L+S rates, ToP rates

Italy: IMER

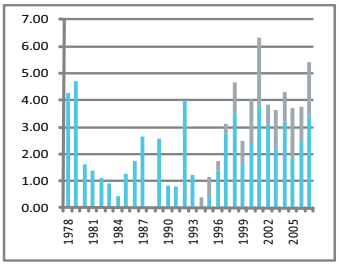
Anorectal atresia/stenosis



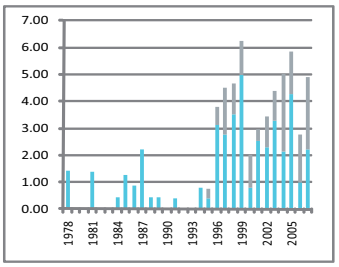
Hypospadias



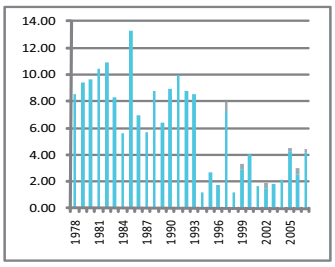
Renal agenesis



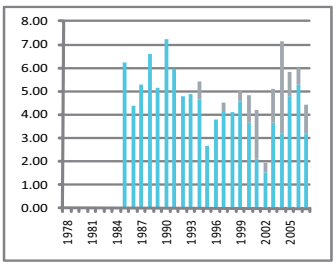
Cystic kidney



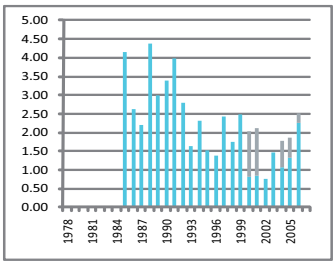
Polydactyly, preaxial



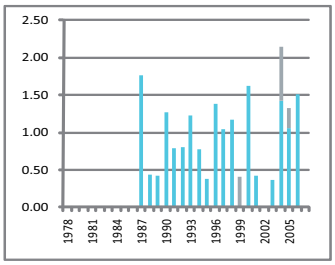
Limb reduction defects



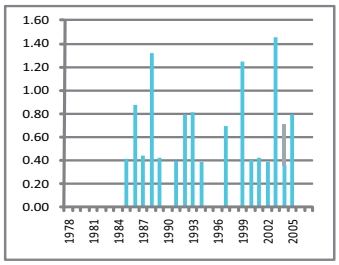
Limb reduction defects - transverse



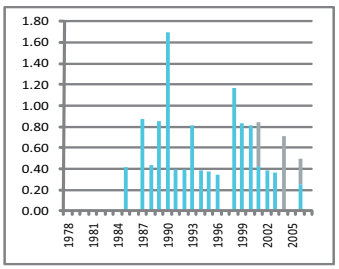
Limb reduction defects - preaxial



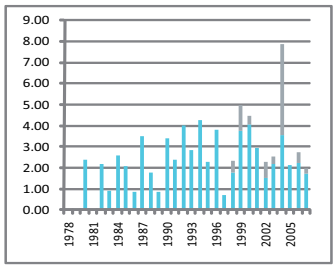
Limb reduction defects - postaxial



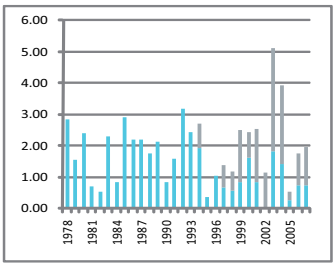
Limb reduction defects - intercalary



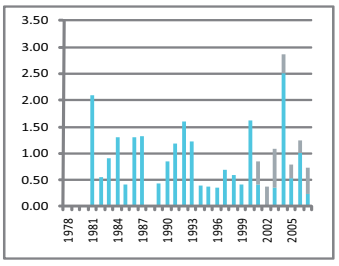
Diaphragmatic hernia



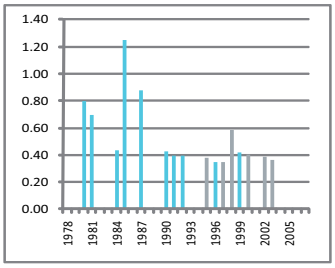
Omphalocele



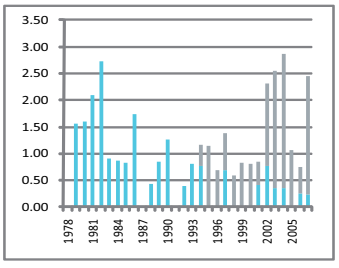
Gastroschisis



Prune belly sequence



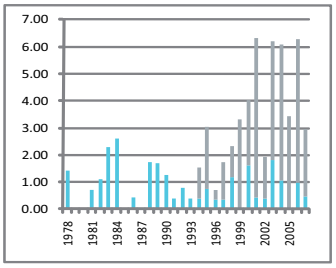
Trisomy 13



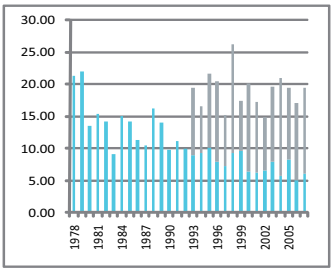
Note: L+S rates, ToP rates

Italy: IMER

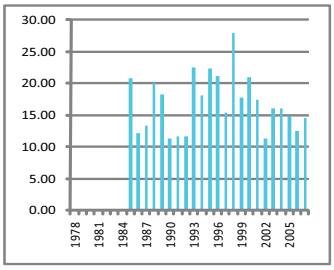
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Italy: North East

North East Italy Registry of Congenital Malformations

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

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

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

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

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

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

Addresses and Staff:
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Maurizio Clementi, MD, Programme Director, from May 24, 2010
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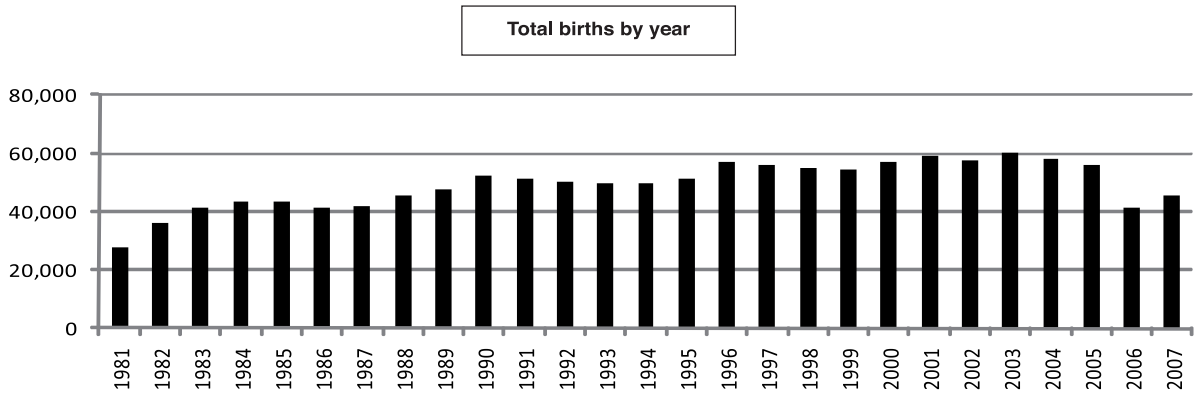
Italy: North East



Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	13	61.9	Cystic kidney	1	20.0
Spina bifida	24	52.2	Limb reduction defects	24	34.8
Encephalocele	1	33.3	Diaphragmatic hernia	5	19.2
Holoprosencephaly	9	56.3	Omphalocele	8	57.1
Hydrocephaly	19	38.0	Gastroschisis	2	18.2
Hypoplastic left heart syndrome	6	27.3	Trisomy 13	12	66.7
Cleft palate without cleft lip	9	7.7	Trisomy 18	23	82.1
Cleft lip with or without cleft palate	13	10.3	Down syndrome	83	35.5
Renal agenesis	9	75.0			

Total ToPs with births defects = 419 (Ratio ToPs/Births: 2.93 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy: North East, 2007

Live births (LB)	45,478
Stillbirths (SB)	91
Total births	45,569
Number of terminations of pregnancy (ToP) for birth defects	143

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	0	5	1.76
Spina bifida	3	0	13	3.51
Encephalocele	0	0	0	0.00
Microcephaly	1	0	1	0.44
Holoprosencephaly	1	1	3	1.10
Hydrocephaly	3	0	3	1.32
Anophthalmos	1	0	0	0.22
Microphthalmos	0	0	3	0.66
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.22
Microtia	7	0	0	1.54
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	0	0	0	0.00
Tetralogy of Fallot	4	0	0	0.88
Hypoplastic left heart syndrome	1	0	0	0.22
Coarctation of aorta	5	0	0	1.10
Choanal atresia, bilateral	4	0	5	1.98
Cleft palate without cleft lip	28	1	4	7.24
Cleft lip with or without cleft palate	31	0	2	7.24
Oesophageal atresia/stenosis with or without fistula	8	0	0	1.76
Small intestine atresia/stenosis	9	0	1	2.19
Anorectal atresia/stenosis	8	0	0	1.76
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	21	0	0	4.61
Epispadias	1	0	0	0.22
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	0	0	3	0.66
Cystic kidney	0	0	0	0.00
Bladder exstrophy	2	0	0	0.44
Polydactyly, preaxial	9	0	0	1.98
Total Limb reduction defects (include unspecified)	10	0	4	3.07
Transverse	4	0	1	1.10
Preaxial	3	0	0	0.66
Postaxial	0	0	0	0.00
Intercalary	1	0	0	0.22
Mixed	0	0	0	0.00
Unspecified	2	0	3	1.10
Diaphragmatic hernia	8	0	3	2.41
Omphalocele	3	0	2	1.10
Gastroschisis	2	0	0	0.44
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	3	1.10
Trisomy 18	0	0	5	1.10
Down syndrome, all ages (include age unknown)	45	0	25	15.36
<20	0	0	0	nr
20-24	1	0	0	nr
25-29	4	0	2	nr
30-34	11	0	5	nr
35-39	11	0	10	nr
40-44	6	0	7	nr
45+	1	0	1	nr
unknown	11	0	0	---

nr = not reported

Italy: North East, Previous years rates 1981 - 2007

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

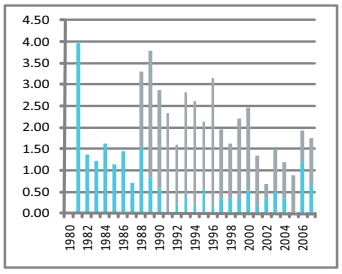
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births		**64,029**	**211,111**	**246,460**	**263,441**	**282,738**	**261,484**
Anencephaly		2.50	1.23	2.76	2.54	1.66	1.42
Spina bifida		4.06	3.69	2.96	3.26	3.82	3.17
Encephalocele		0.94	0.81	0.97	0.95	0.67	0.31
Microcephaly		0.62	0.33	0.28	0.65	1.59	1.57
Holoprosencephaly		0.00	0.05	0.65	1.02	1.17	0.92
Hydrocephaly		0.62	1.23	2.64	3.99	5.80	3.79
Anophthalmos		0.00	0.71	0.28	0.27	0.14	0.27
Microphthalmos		0.00	0.00	0.28	0.87	0.78	0.80
Unspecified Anophthalmos / Microphthalmos		0.00	0.00	0.00	0.00	0.00	0.00
Anotia		0.31	0.14	0.24	0.27	0.11	0.19
Microtia		2.66	2.18	1.54	1.78	1.31	1.34
Unspecified Anotia / Microtia		0.00	0.00	0.16	0.08	0.25	0.31
Transposition of great vessels		0.00	0.05	0.16	1.59	2.23	1.95
Tetralogy of Fallot		0.00	0.38	0.89	2.62	3.25	3.40
Hypoplastic left heart syndrome		0.00	0.00	0.32	2.20	1.03	1.42
Coarctation of aorta		0.00	0.05	0.45	1.33	3.15	2.10
Choanal atresia, bilateral		0.00	0.24	0.32	0.46	1.31	1.11
Cleft palate without cleft lip		1.09	5.92	5.56	4.18	5.55	7.34
Cleft lip with or without cleft palate		9.84	8.62	8.40	7.48	7.39	8.99
Oesophageal atresia / stenosis with or without fistula		3.12	2.18	2.19	2.81	2.83	2.79
Small intestine atresia / stenosis		0.16	0.66	1.05	0.84	1.59	3.48
Anorectal atresia / stenosis		2.34	2.98	2.72	2.28	3.32	2.37
Undescended testis (36 weeks of gestation or later)		nr	nr	nr	nr	nr	nr
Hypospadias		9.06	6.06	6.65	5.81	20.76	13.50
Epispadias		0.00	0.14	0.08	0.15	0.42	0.04
Indeterminate sex		nr	nr	nr	nr	nr	nr
Renal agenesis		0.31	0.71	0.93	0.46	0.60	0.57
Cystic kidney		0.00	0.00	0.04	0.53	1.31	0.73
Bladder exstrophy		0.16	0.24	0.45	0.15	0.28	0.27
Polydactyly, preaxial		2.34	1.75	2.64	2.20	1.77	1.61
'Total Limb reduction defects (include unspecified)		5.93	5.68	6.21	5.50	4.67	4.13
Transverse		3.75	3.08	3.21	2.92	2.33	1.11
Preaxial		0.00	0.00	0.53	0.87	0.46	0.38
Postaxial		0.00	0.05	0.12	0.23	0.25	0.19
Intercalary		0.94	0.57	1.05	0.57	0.35	0.23
Mixed		1.25	1.99	0.16	0.19	0.11	0.11
Unspecified		0.00	0.00	1.10	0.76	1.17	2.03
Diaphragmatic hernia		0.16	0.76	0.45	0.65	1.45	1.99
Omphalocele		1.56	1.23	1.46	1.25	1.27	1.26
Gastroschisis		1.56	0.66	0.69	0.57	0.53	0.88
Unspecified Omphalocele / Gastroschisis		nr	nr	nr	nr	nr	nr
Prune belly sequence		0.00	0.05	0.16	0.34	0.04	0.00
Trisomy 13		0.78	0.81	0.57	0.99	1.27	1.19
Trisomy 18		0.47	1.28	1.95	2.77	2.55	2.03
Down syndrome, all ages (include age unknown)		15.15	14.68	15.58	17.12	17.30	16.71
<20		nr	nr	nr	nr	nr	nr
20-24		nr	nr	nr	nr	nr	nr
25-29		nr	nr	nr	nr	nr	nr
30-34		nr	nr	nr	nr	nr	nr
35-39		nr	nr	nr	nr	nr	nr
40-44		nr	nr	nr	nr	nr	nr
45+		nr	nr	nr	nr	nr	nr
unknown		---	---	---	---	---	---

nr = not reported
* data include less than 5 years

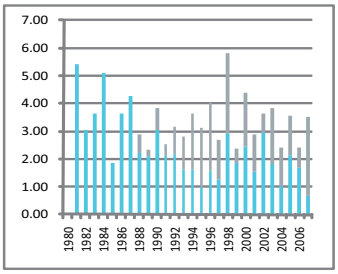
Italy: North East

'Time trends 1981-2007 (Birth prevalence rates per 10,000)

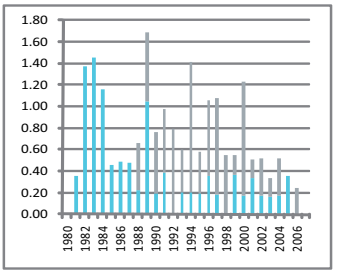
Anencephaly



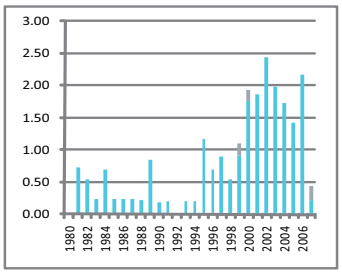
Spina Bifida



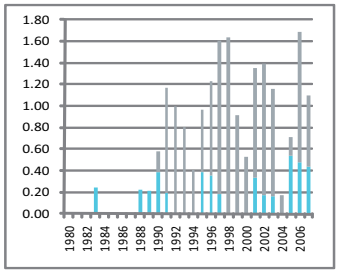
Encephalocele



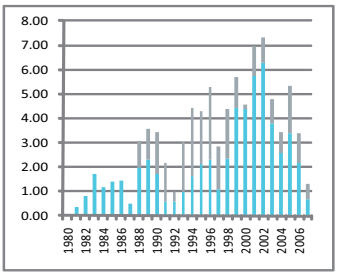
Microcephaly



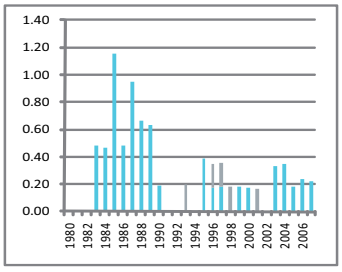
Holoprosencephaly



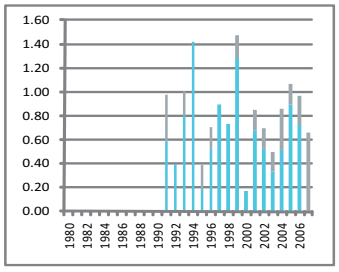
Hydrocephaly



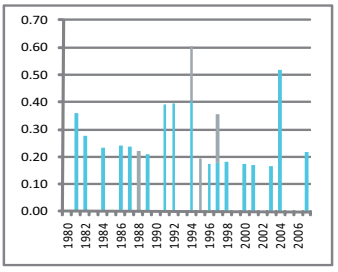
Anophthalmos



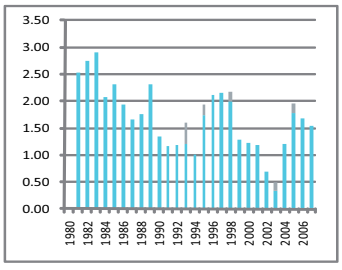
Microphthalmos



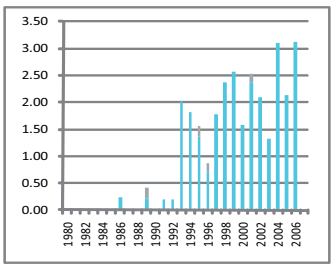
Anotia



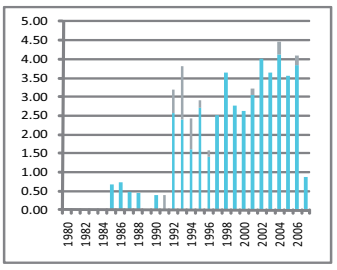
Microtia



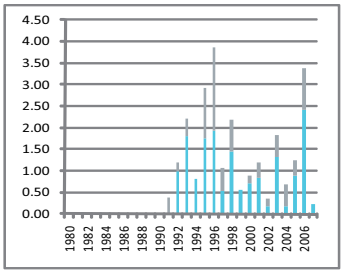
Transposition of great vessels



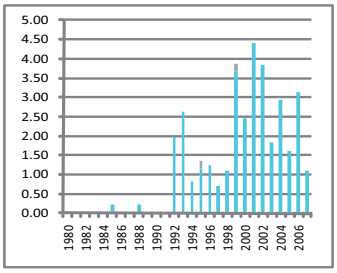
Tetralogy of Fallot



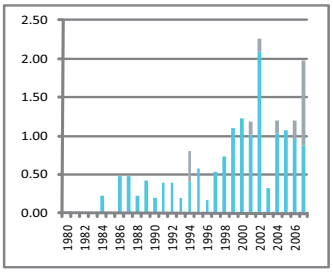
Hypoplastic left heart syndrome



Coarctation of aorta



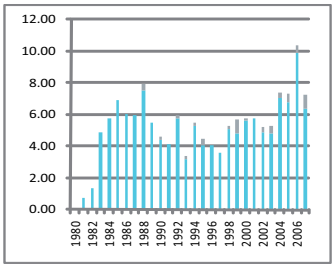
Choanal atresia, bilateral



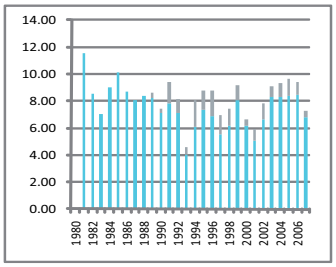
Note: L+S rates, ToP rates

Italy: North East

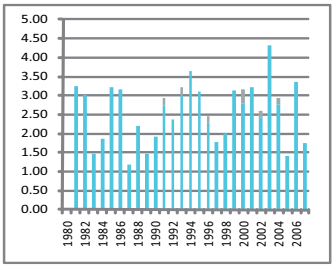
Cleft palate without cleft lip



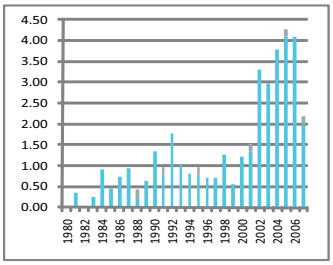
Cleft lip with or without cleft palate



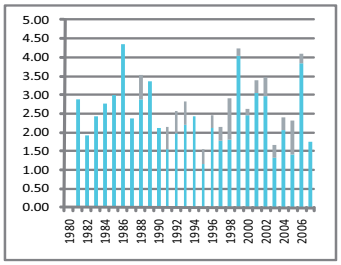
Oesophageal atresia/stenosis with or without fistula



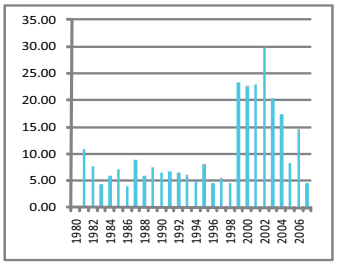
Small intestine atresia/stenosis



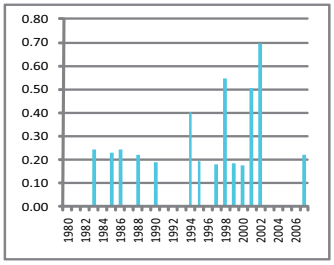
Anorectal atresia/stenosis



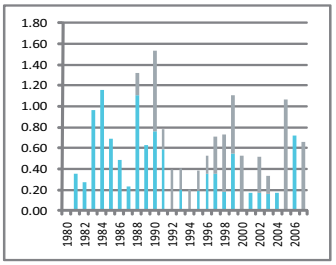
Hypospadias



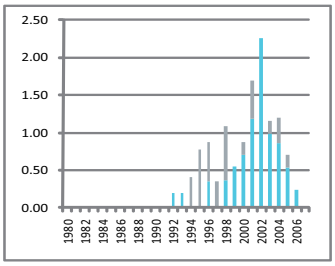
Epispadias



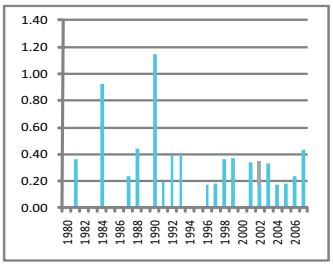
Renal agenesis



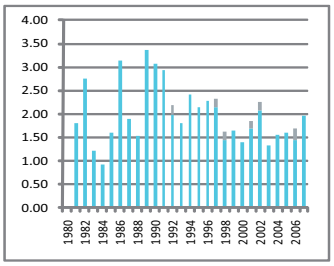
Cystic kidney



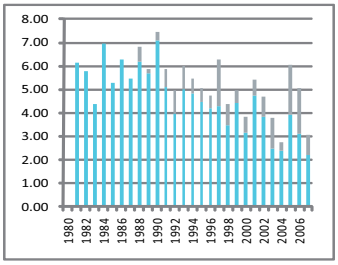
Bladder exstrophy



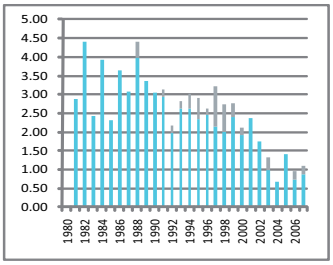
Polydactyly, preaxial



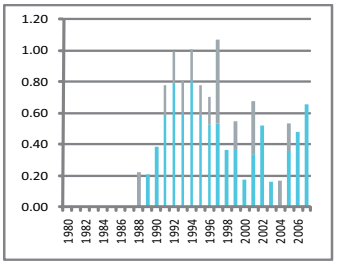
Limb reduction defects



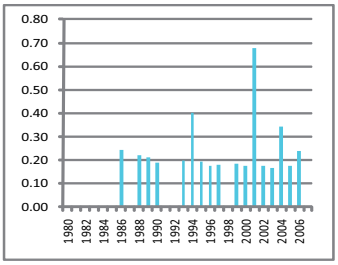
Limb reduction defects - transverse



Limb reduction defects - preaxial



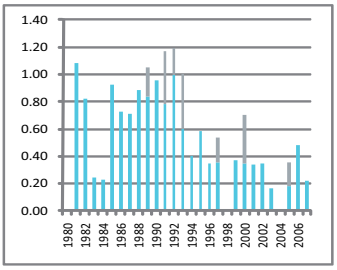
Limb reduction defects - postaxial



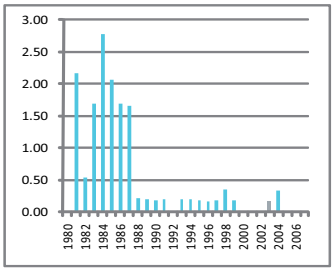
Note: L+S rates, ToP rates

Italy: North East

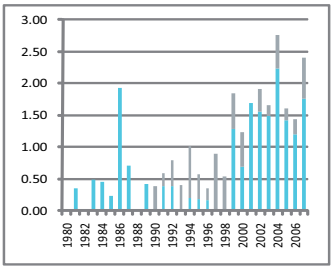
Limb reduction defects - intercalary



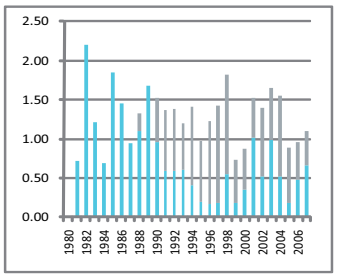
Limb reduction defects - mixed



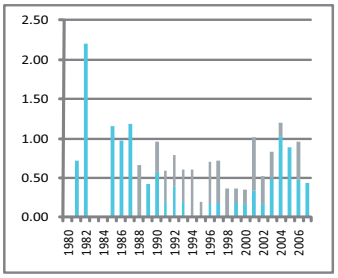
Diaphragmatic hernia



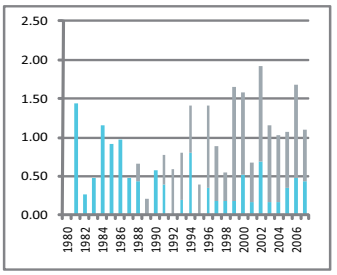
Omphalocele



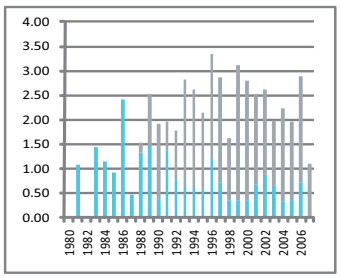
Gastroschisis



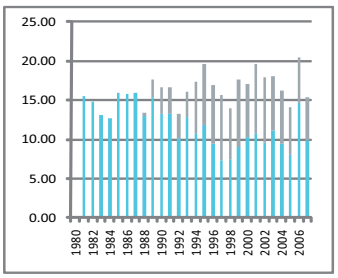
Trisomy 13



Trisomy 18



Down Syndrome



Note: L+S rates, ToP rates

Italy - Tuscany: RTDC
Tuscany Registry of Congenital Defects

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

Size and coverage:
The Programme is population based, involves all the regional hospitals and the coverage is around 95% of all births in the Tuscany region (approximately 3.5 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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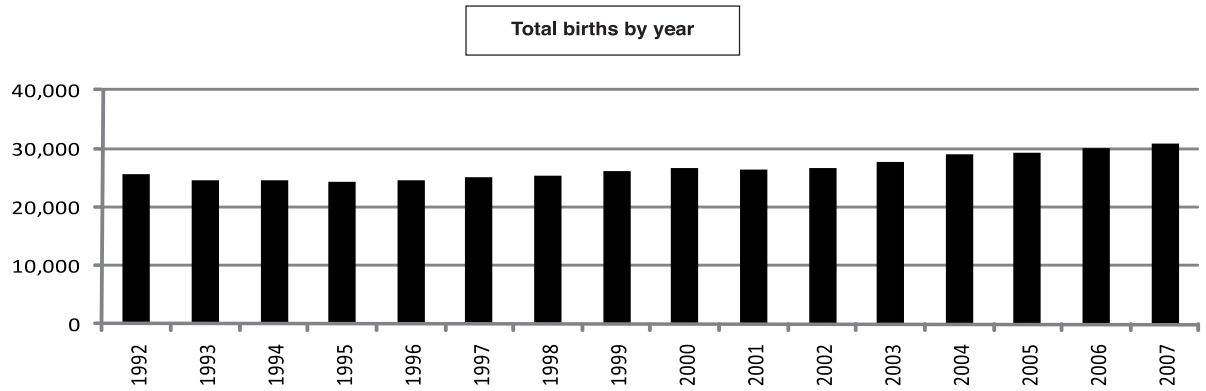
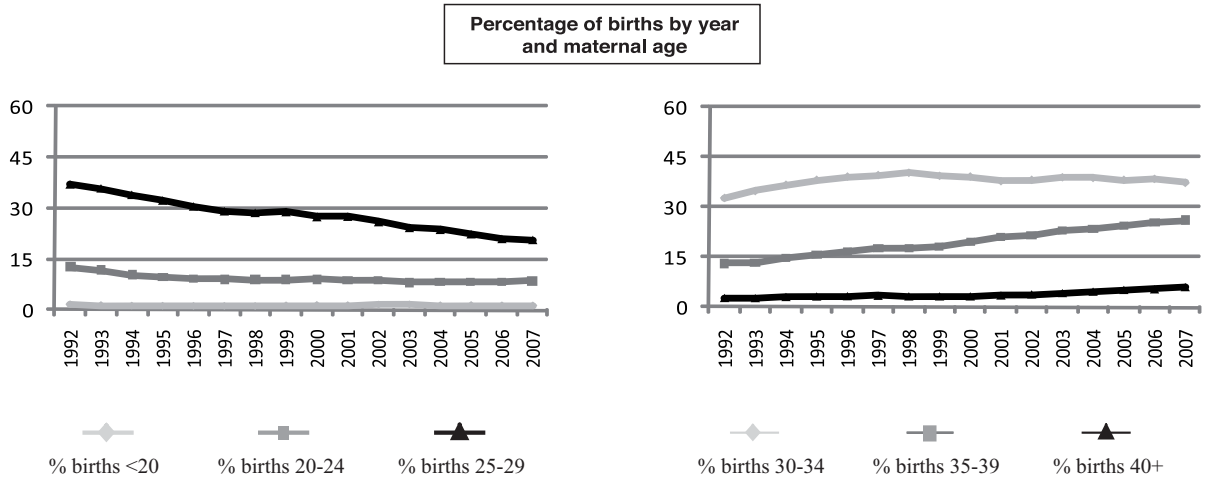
Fax: 39-050-3152095
E-mail: apier@ifc.cnr.it

Website: www.rtdc.it

Italy: Tuscany





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	16	80.0	Cystic kidney	5	13.5
Spina bifida	18	81.8	Limb reduction defects	9	23.1
Encephalocele	5	62.5	Diaphragmatic hernia	3	27.3
Holoprosencephaly	11	91.7	Omphalocele	13	76.5
Hydrocephaly	21	65.6	Gastroschisis	5	50.0
Hypoplastic left heart syndrome	6	33.3	Trisomy 13	10	76.9
Cleft palate without cleft lip	1	3.4	Trisomy 18	22	84.6
Cleft lip with or without cleft palate	10	22.2	Down syndrome	93	69.4
Renal agenesis	3	50.0			

Total ToPs with births defects = 319 (Ratio ToPs/Births: 3.52 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Italy:Tuscany, 2007

Live births (LB)	30,862
Stillbirths (SB)	82
Total births	30,944
Number of terminations of pregnancy (ToP) for birth defects	135

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	3	0.97
Spina bifida	2	0	12	4.52
Encephalocele	1	0	3	1.29
Microcephaly	1	0	0	0.32
Holoprosencephaly	1	0	7	2.59
Hydrocephaly	1	0	9	3.23
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	1	0.97
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	0	0	3	0.97
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	6	0	1	2.26
Tetralogy of Fallot	7	0	1	2.59
Hypoplastic left heart syndrome	4	0	2	1.94
Coarctation of aorta	9	0	0	2.91
Choanal atresia, bilateral	2	0	0	0.65
Cleft palate without cleft lip	12	0	1	4.20
Cleft lip with or without cleft palate	8	0	6	4.52
Oesophageal atresia/stenosis with or without fistula	2	0	1	0.97
Small intestine atresia/stenosis	4	0	0	1.29
Anorectal atresia/stenosis	2	0	0	0.65
Undescended testis (36 weeks of gestation or later)	11	0	0	3.55
Hypospadias	21	0	0	6.79
Epispadias	0	0	0	0.00
Indeterminate sex	0	0	0	0.00
Renal agenesis	2	0	1	0.97
Cystic kidney	8	0	4	3.88
Bladder exstrophy	2	0	1	0.97
Polydactyly, preaxial	4	2	0	1.94
Total Limb reduction defects (include unspecified)	9	0	4	4.20
Transverse	6	0	2	2.59
Preaxial	1	0	0	0.32
Postaxial	0	0	0	0.00
Intercalary	0	0	0	0.00
Mixed	0	0	1	0.32
Unspecified	2	0	1	0.97
Diaphragmatic hernia	4	0	1	1.62
Omphalocele	2	0	7	2.91
Gastroschisis	2	0	3	1.62
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	1	0	3	1.29
Trisomy 18	2	0	11	4.20
Down syndrome, all ages (include age unknown)	14	1	29	14.22
<20	0	0	0	0.00
20-24	1	0	0	3.79
25-29	0	0	1	1.56
30-34	3	0	3	5.20
35-39	6	1	15	27.29
40-44	3	0	9	66.33
45+	0	0	0	0.00
unknown	1	0	1	---

Italy: Tuscany, Previous years rates 1992 - 2007

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

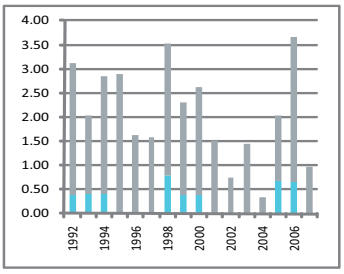
	1974-1977	1978-1982	1983-19871988-1992*	1993-1997	1998-2002	2003-2007
Total births			**25,670**	**123,284**	**131,120**	**147,119**
Anencephaly			3.12	2.19	2.14	1.70
Spina bifida			2.73	2.43	3.36	2.99
Encephalocele			1.17	1.14	0.46	0.61
Microcephaly			1.95	0.97	0.76	0.82
Holoprosencephaly			0.78	0.57	0.92	1.36
Hydrocephaly			5.06	2.68	2.44	4.42
Anophthalmos			0.00	0.00	0.31	0.14
Microphthalmos			0.39	0.49	0.53	0.68
Unspecified Anophthalmos / Microphthalmos			0.00	0.00	0.08	0.00
Anotia			0.39	0.41	0.15	0.34
Microtia			0.00	0.65	0.38	0.61
Unspecified Anotia / Microtia			0.00	0.00	0.00	0.00
Transposition of great vessels			1.95	1.78	2.75	2.99
Tetralogy of Fallot			2.34	2.35	2.59	2.85
Hypoplastic left heart syndrome			2.73	1.70	2.36	2.04
Coarctation of aorta			3.51	2.19	2.90	2.24
Choanal atresia, bilateral			0.00	0.08	0.46	0.48
Cleft palate without cleft lip			3.12	3.81	3.58	4.15
Cleft lip with or without cleft palate			10.52	5.92	7.02	5.10
Oesophageal atresia / stenosis with or without fistula			3.12	2.27	2.36	1.97
Small intestine atresia / stenosis			1.56	0.73	0.53	1.50
Anorectal atresia / stenosis			1.95	1.62	2.59	1.97
Undescended testis (36 weeks of gestation or later)			1.95	3.81	10.60	5.91
Hypospadias			6.23	4.06	5.41	6.66
Epispadias			0.39	0.24	0.23	0.20
Indeterminate sex			0.00	1.05	0.46	0.41
Renal agenesis			2.34	1.87	0.76	0.75
Cystic kidney			3.90	3.57	3.28	4.49
Bladder exstrophy			1.17	0.08	0.23	0.27
Polydactyly, preaxial			0.78	0.81	1.37	1.09
'Total Limb reduction defects (include unspecified)			4.29	5.11	5.95	5.03
Transverse			3.51	3.49	3.51	2.79
Preaxial			0.39	0.24	0.46	0.54
Postaxial			0.39	0.08	0.38	0.20
Intercalary			0.00	0.32	0.69	0.41
Mixed			0.00	0.49	0.46	0.07
Unspecified			0.00	0.00	0.46	1.43
Diaphragmatic hernia			1.56	1.62	1.83	1.70
Omphalocele			2.34	1.54	1.75	1.84
Gastroschisis			0.39	0.32	0.46	1.09
Unspecified Omphalocele / Gastroschisis			1.17	0.16	0.38	0.00
Prune belly sequence			0.39	0.16	0.00	0.00
Trisomy 13			0.00	0.65	1.07	1.50
Trisomy 18			2.34	3.33	2.67	3.06
Down syndrome, all ages (include age unknown)			10.52	16.14	16.09	15.97
<20			0.00	0.00	0.00	0.00
20-24			3.10	8.33	5.20	3.30
25-29			6.39	9.49	5.83	2.75
30-34			4.81	14.31	10.87	6.07
35-39			30.13	27.11	26.20	27.66
40-44			46.44	92.70	136.37	104.01
45+			416.67	88.50	51.81	119.05
unknown			---	---	---	---

* data include less than 5 years

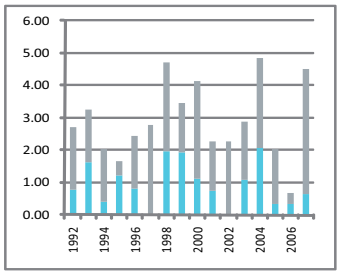
Italy: Tuscany

Time trends 1992-2007 (Birth prevalence rates per 10,000)

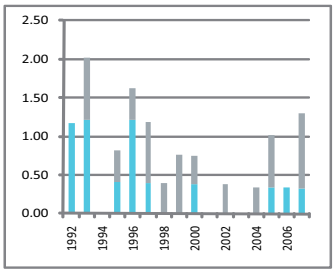
Anencephaly



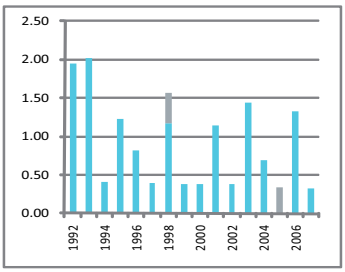
Spina Bifida



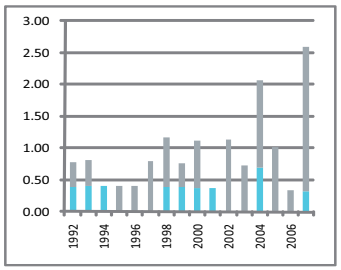
Encephalocele



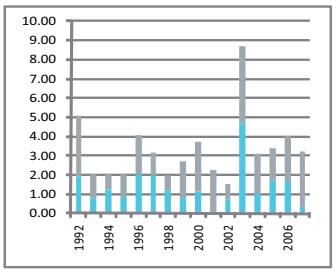
Microcephaly



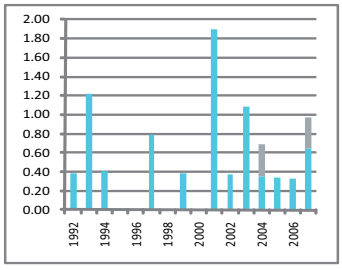
Holoprosencephaly



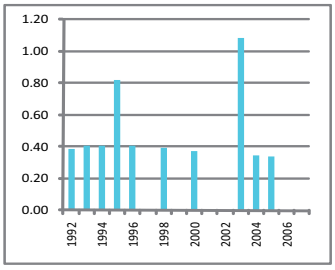
Hydrocephaly



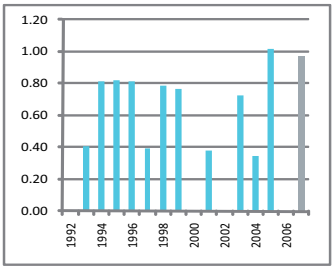
Microphthalmos



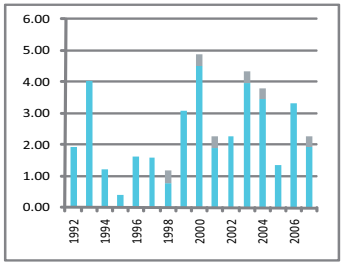
Anotia



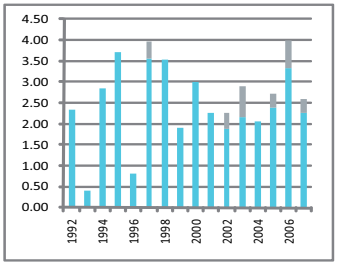
Microtia



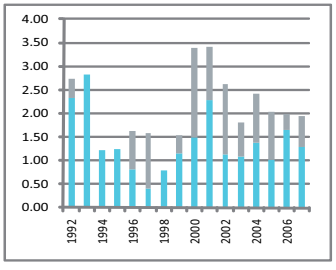
Transposition of great vessels



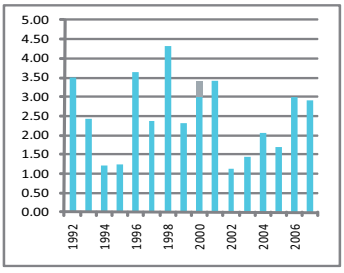
Tetralogy of Fallot



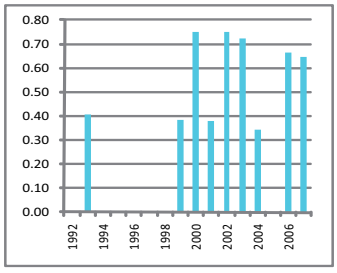
Hypoplastic left heart syndrome



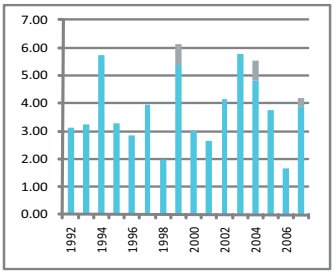
Coarctation of aorta



Choanal atresia, bilateral



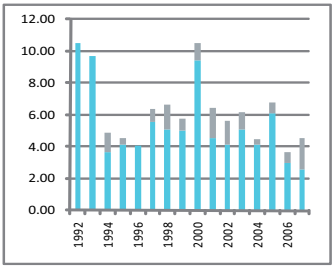
Cleft palate without cleft lip



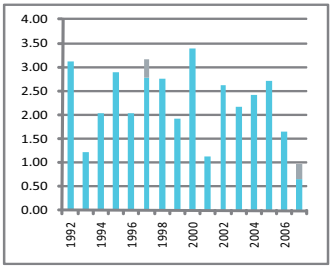
Note: L+S rates, ToP rates

Italy: Tuscany

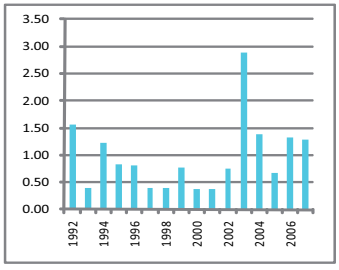
Cleft lip with or without cleft palate



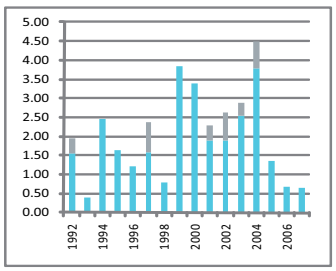
Oesophageal atresia/stenosis with or without fistula



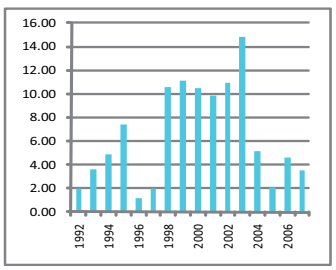
Small intestine atresia/stenosis



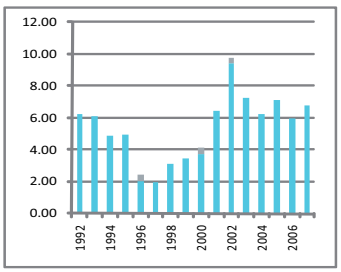
Anorectal atresia/stenosis



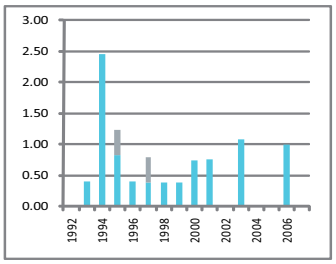
Undescended testis



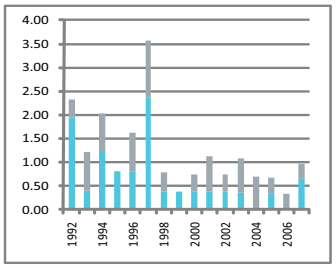
Hypospadias



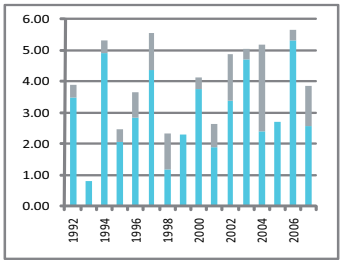
Indeterminate sex



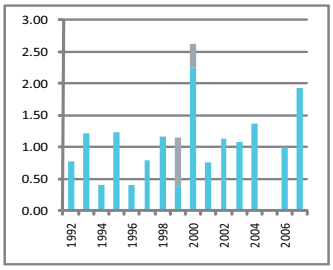
Renal agenesis



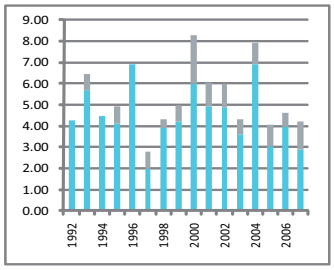
Cystic kidney



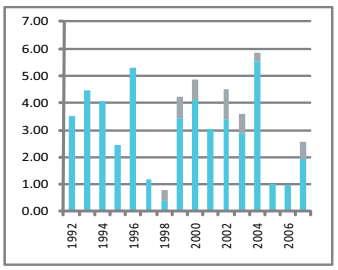
Polydactyly, preaxial



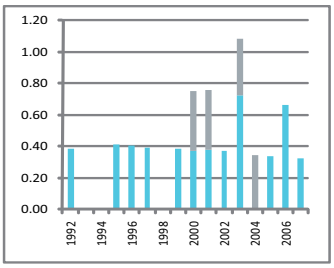
Limb reduction defects



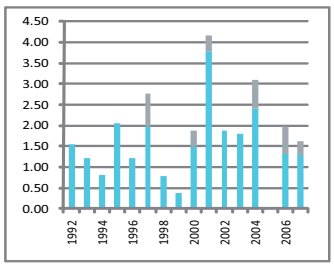
Limb reduction defects - transverse



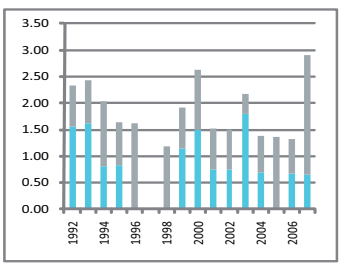
Limb reduction defects - preaxial



Diaphragmatic hernia



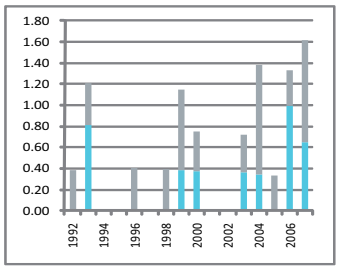
Omphalocele



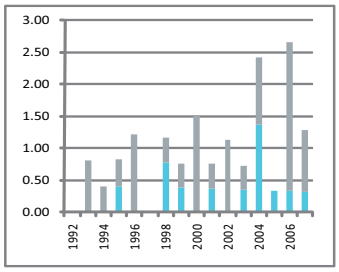
Note: L+S rates, ToP rates

Italy: Tuscany

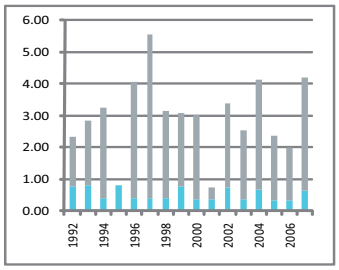
Gastroschisis



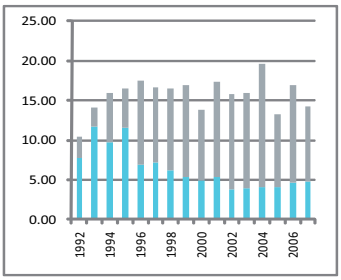
Trisomy 13



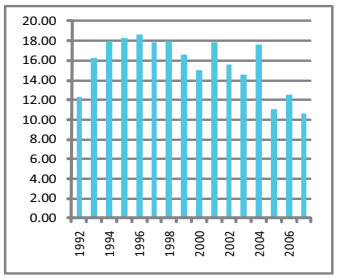
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Japan: JAOG

Japan Association of Obstetricians and Gynaecologists

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

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

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

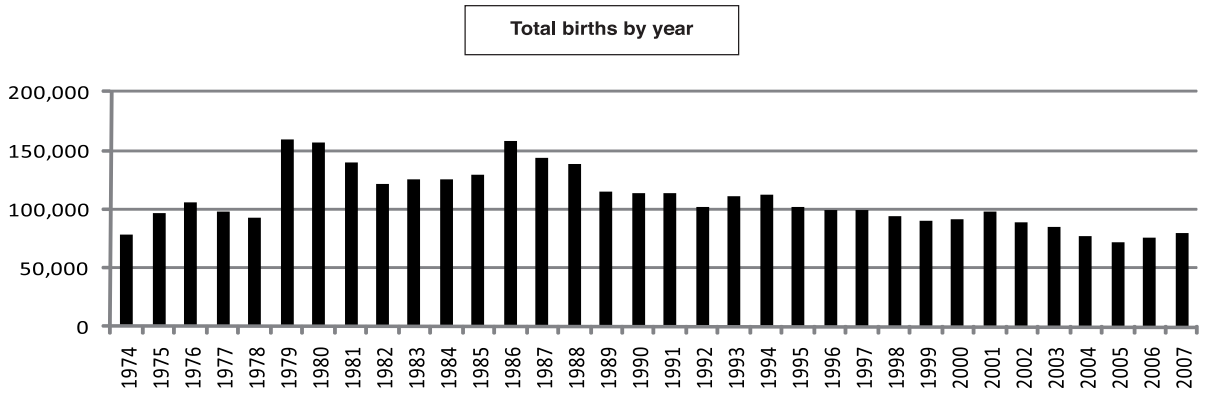
Sources of ascertainment:
Reports are obtained from delivery units and pediatric clinics of the participating hospitals.

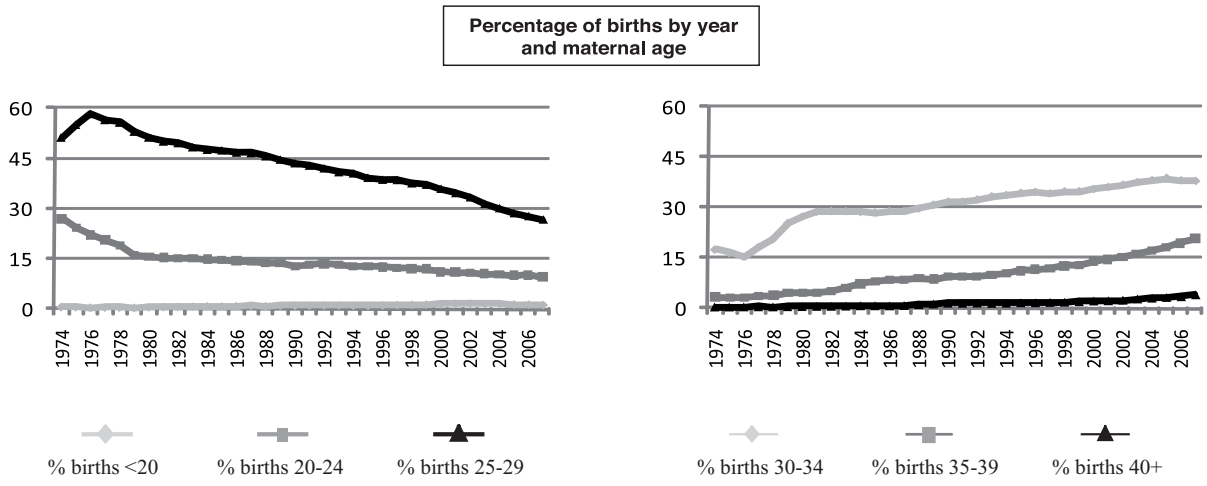
Exposure information:
Exposure to drugs, X-ray and viral infections are available.

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

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

Japan: JAOG


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


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

Japan JAOG, 2007

Live births (LB)	79,095
Stillbirths (SB)	493
Total births	79,588
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	6	nr	0.75
Spina bifida	33	5	nr	4.77
Encephalocele	7	0	nr	0.88
Microcephaly	17	1	nr	2.26
Holoprosencephaly	5	4	nr	1.13
Hydrocephaly	59	4	nr	7.92
Anophthalmos	2	0	nr	0.25
Microphthalmos	9	2	nr	1.38
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	18	1	nr	2.39
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	34	1	nr	4.40
Tetralogy of Fallot	52	0	nr	6.53
Hypoplastic left heart syndrome	22	3	nr	3.14
Coarctation of aorta	37	3	nr	5.03
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	36	0	nr	4.52
Cleft lip with or without cleft palate	161	8	nr	21.23
Oesophageal atresia/stenosis with or without fistula	42	6	nr	6.03
Small intestine atresia/stenosis	49	3	nr	6.53
Anorectal atresia/stenosis	45	9	nr	6.78
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	20	1	nr	2.64
Epispadias	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	13	6	nr	2.39
Cystic kidney	26	2	nr	3.52
Bladder exstrophy	2	0	nr	0.25
Polydactyly, preaxial	48	1	nr	6.16
Total Limb reduction defects (include unspecified)	19	5	nr	3.02
Transverse	1	0	nr	0.13
Preaxial	3	0	nr	0.38
Postaxial	2	1	nr	0.38
Intercalary	7	1	nr	1.01
Mixed	3	2	nr	0.63
Unspecified	3	1	nr	0.50
Diaphragmatic hernia	40	4	nr	5.53
Omphalocele	33	8	nr	5.15
Gastroschisis	14	1	nr	1.88
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	1	nr	0.13
Trisomy 13	15	3	nr	2.26
Trisomy 18	59	23	nr	10.30
Down syndrome, all ages (include age unknown)	93	3	nr	12.06
<20	0	0	nr	0.00
20-24	1	0	nr	1.31
25-29	12	2	nr	6.59
30-34	34	0	nr	11.32
35-39	33	0	nr	19.93
40+	13	1	nr	44.39
unknown	0	0	nr	---

nr = not reported

Japan: JAOG, Previous years rates 1974 - 2007

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

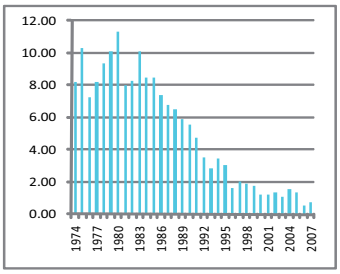
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**378,609**	**669,528**	**682,593**	**582,921**	**522,804**	**462,504**	**390,016**
Anencephaly	8.48	9.51	8.16	5.34	2.64	1.49	1.05
Spina bifida	1.69	2.30	2.93	3.31	3.71	4.56	5.13
Encephalocele	1.08	1.03	1.30	1.08	0.98	0.78	0.77
Microcephaly	0.85	1.11	1.17	1.44	1.45	1.34	1.59
Holoprosencephaly	nr	nr	nr	nr	0.83*	1.17	1.44
Hydrocephaly	2.59	3.44	4.63	6.69	6.89	7.50	7.62
Anophthalmos	0.77	0.82	0.82	0.48	0.19	0.24	0.46
Microphthalmos	0.53	0.63	0.51	0.69	0.48	0.45	0.67
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	1.16	1.05	1.13	1.10	1.24	1.32	1.41
Unspecified Anotia / Microtia	nr	nr	nr	nr	nr	nr	0.00*
Transposition of great vessels	nr	nr	nr	nr	1.61*	2.53	4.44
Tetralogy of Fallot	nr	nr	nr	nr	2.02*	3.14	5.64
Hypoplastic left heart syndrome	nr	nr	nr	nr	1.01*	1.84	3.77
Coarctation of aorta	nr	nr	nr	nr	0.60*	2.31	3.95
Choanal atresia, bilateral	nr	nr	nr	nr	nr	nr	0.00*
Cleft palate without cleft lip	12.65	11.58	5.00	5.88	4.49	4.30	4.72
Cleft lip with or without cleft palate	14.95	13.16	13.73	15.20	16.07	17.90	20.18
Oesophageal atresia / stenosis with or without fistula	nr	1.15	1.33	1.80	2.52	3.83	5.03
Small intestine atresia / stenosis	nr	nr	nr	nr	3.03*	5.19	7.10
Anorectal atresia / stenosis	3.80	3.93	3.96	4.29	4.19	4.82	6.36
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	nr
Hypospadias	1.45	2.15	2.43	2.71	2.83	3.81	3.85
Epispadias	nr	nr	nr	nr	nr	nr	nr
Indeterminate sex	nr	nr	nr	nr	nr	nr	nr
Renal agenesis	nr	nr	nr	1.28*	1.40	1.99	2.38
Cystic kidney	nr	nr	nr	nr	1.91*	3.74	4.36
Bladder exstrophy	0.10*	0.20*	0.16	0.10	0.11	0.28	0.23
Polydactyly, preaxial	nr	nr	nr	5.98*	6.56	6.05	6.85
‘Total Limb reduction defects (include unspecified)	nr	nr	nr	nr	3.33	3.42	3.33
Transverse	nr	nr	nr	nr	0.36	0.32	0.31
Preaxial	nr	nr	nr	nr	0.54	0.63	0.54
Postaxial	nr	nr	nr	nr	0.29	0.30	0.44
Intercalary	nr	nr	nr	nr	1.28	0.93	0.62
Mixed	nr	nr	nr	nr	0.55	0.76	0.95
Unspecified	nr	nr	nr	nr	0.31	0.48	0.49
Diaphragmatic hernia	nr	nr	nr	2.45*	3.14	5.62	5.95
Omphalocele	0.92	1.34	2.01	3.35	2.96	3.44	3.95
Gastroschisis	1.08	0.96	1.00	1.44	1.57	2.36	2.62
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.33	0.21	0.32	0.18
Prune belly sequence	nr	nr	nr	nr	0.06*	0.02	0.03
Trisomy 13	nr	nr	nr	nr	0.70*	1.06	1.87
Trisomy 18	nr	nr	nr	nr	2.89*	5.88	8.31
Down syndrome, all ages (include age unknown)	nr	4.54	5.13	6.16	7.10	9.06	11.18
<20	nr	nr	nr	nr	3.47	5.88	3.62
20-24	nr	nr	nr	nr	2.41	3.04	4.06
25-29	nr	nr	nr	nr	4.15	5.81	5.31
30-34	nr	nr	nr	nr	6.65	7.98	9.87
35-39	nr	nr	nr	nr	17.72	18.60	20.85
40+	nr	nr	nr	nr	55.30	54.21	49.54
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 4 years or 5 years

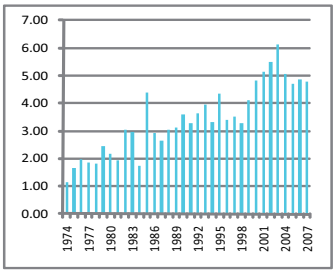
Japan: JAOG

Time trends 1974-2007 (Birth prevalence rates per 10,000)

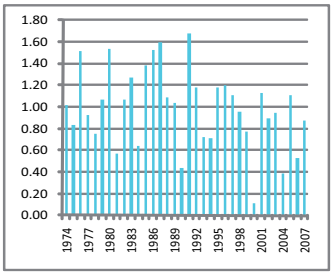
Anencephaly



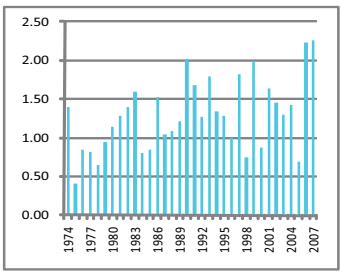
Spina Bifida



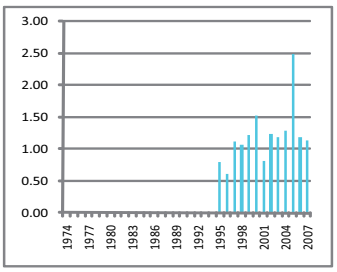
Encephalocele



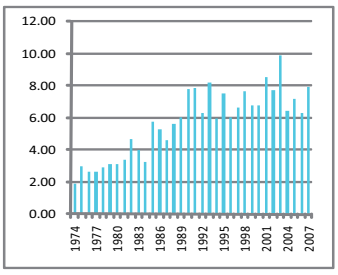
Microcephaly



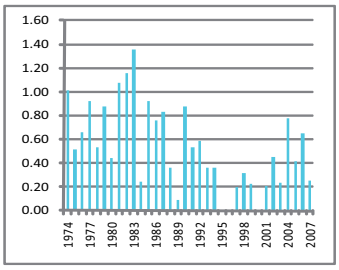
Holoprosencephaly



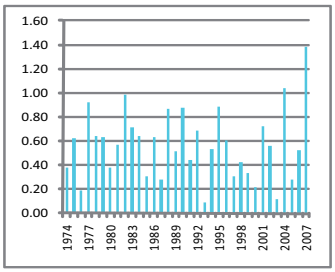
Hydrocephaly



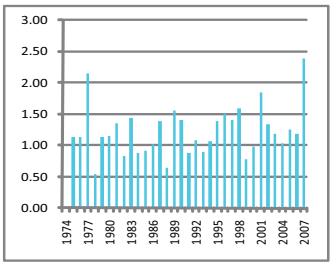
Anophthalmos



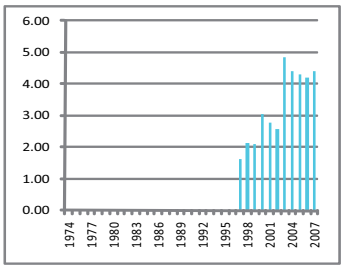
Microphthalmos



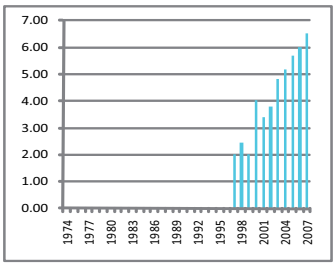
Microtia



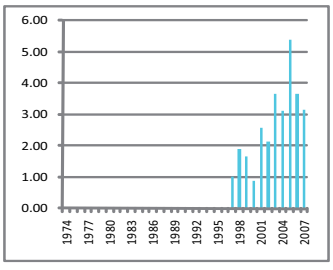
Transposition of great vessels



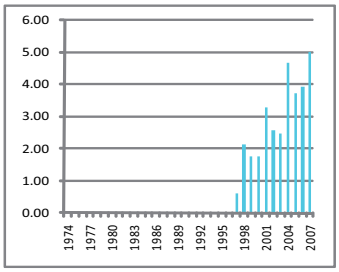
Tetralogy of Fallot



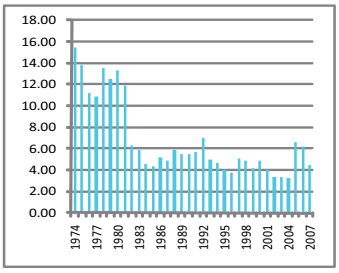
Hypoplastic left heart syndrome



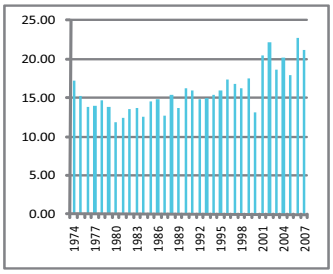
Coarctation of aorta



Cleft palate without cleft lip



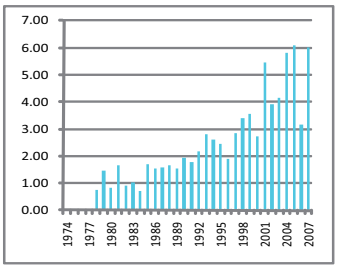
Cleft lip with or without cleft palate



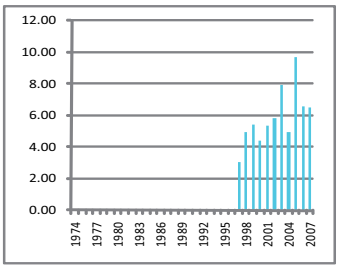
Note: L+S rates

Japan: JAOG

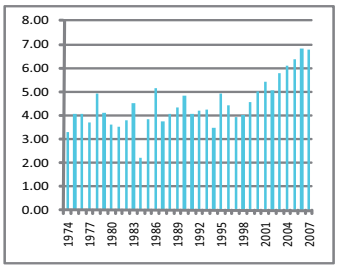
Oesophageal atresia/stenosis with or without fistula



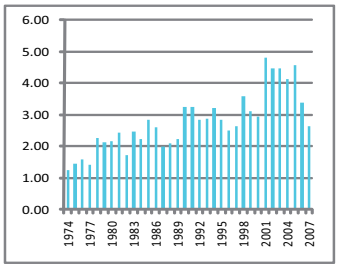
Small intestine atresia/stenosis



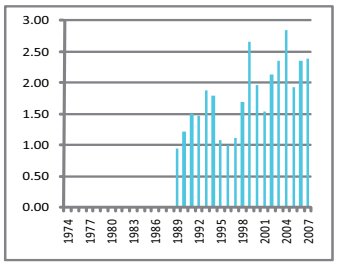
Anorectal atresia/stenosis



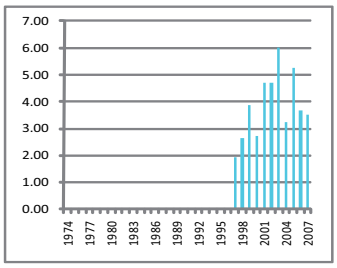
Hypospadias



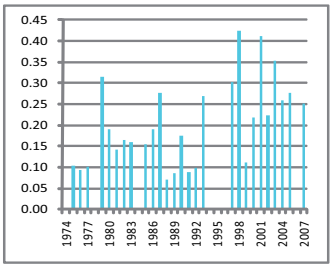
Renal agenesis



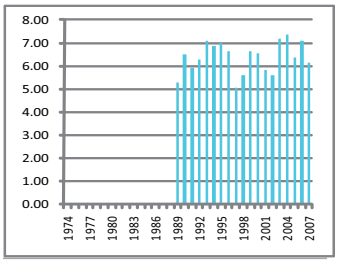
Cystic kidney



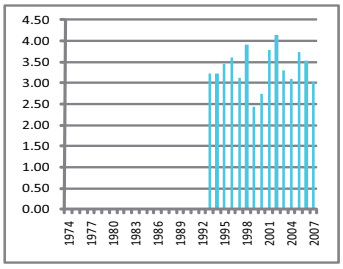
Bladder exstrophy



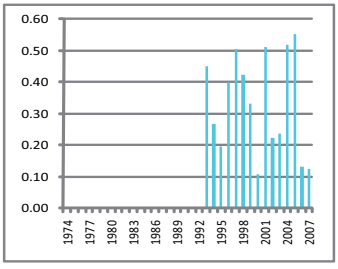
Polydactyly, preaxial



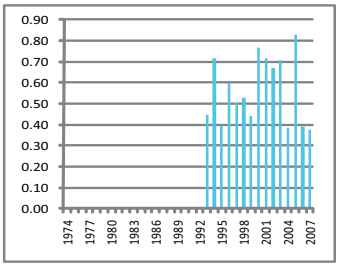
Limb reduction defects



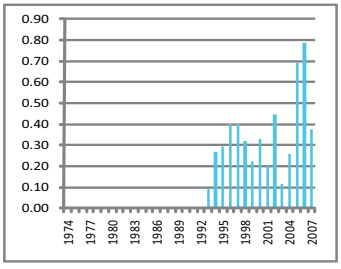
Limb reduction defects - transverse



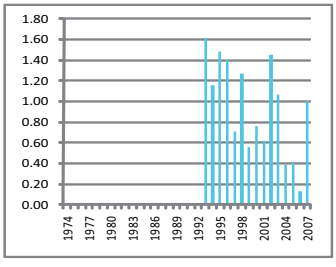
Limb reduction defects - preaxial



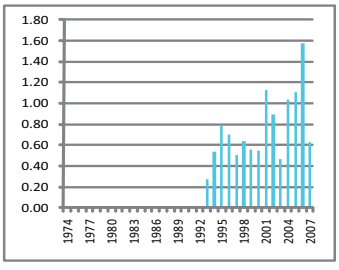
Limb reduction defects - postaxial



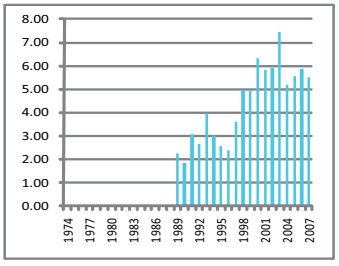
Limb reduction defects - intercalary



Limb reduction defects - mixed



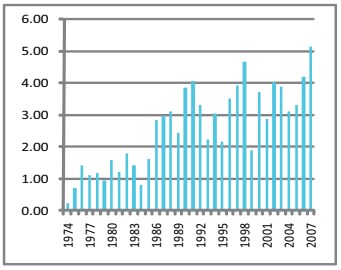
Diaphragmatic hernia



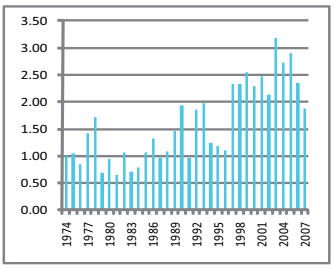
Note: L+S rates

Japan: JAOG

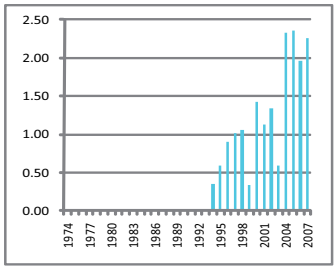
Omphalocele



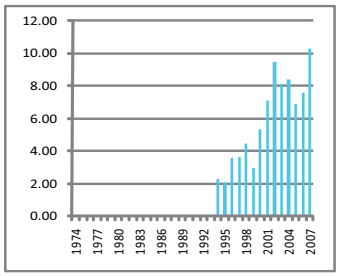
Gastroschisis



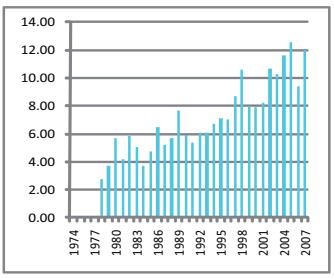
Trisomy 13



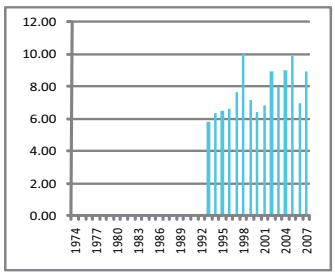
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Malta: MCAR
Malta Congenital Anomalies Register

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

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

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

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

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

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

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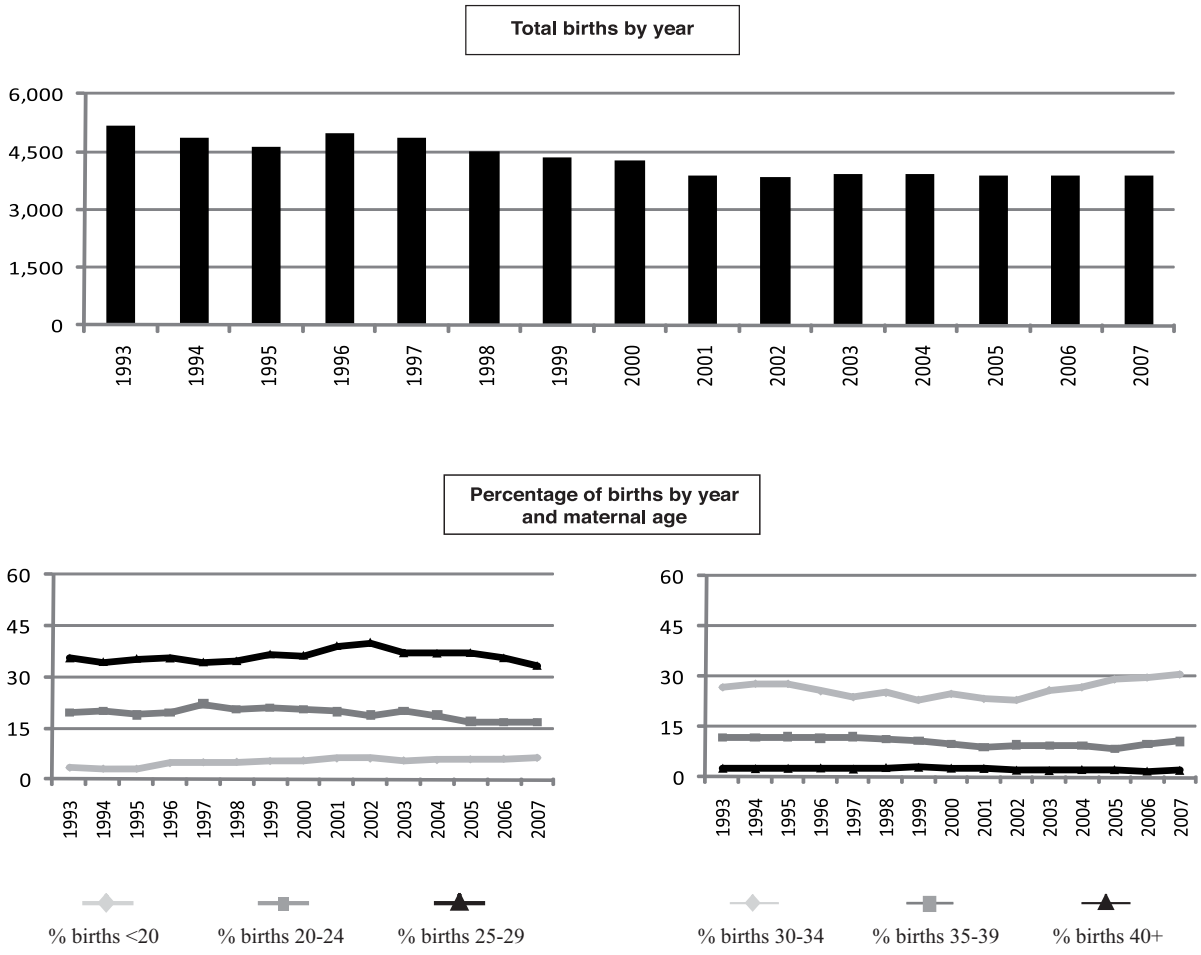
Malta Congenital Anomalies Registry
Department of Health Information and Research
95, Guardamangia Hill
Guardamangia PTA 1313, Malta
Phone: 356 25599000
Fax: 356 25599385
E-mail: miriam.gatt@gov.mt

Malta: MCAR


Total births by year
6,000
4,500
3,000
1,500
0
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
Percentage of births by year and maternal age
60
45
30
15
0
% births <20
% births 20-24
% births 25-29
% births 30-34
% births 35-39
% births 40+

Malta: MCAR, 2007

Live births (LB)	3,886
Stillbirths (SB)	12
Total births	3,898
Number of terminations of pregnancy (ToP) for birth defects	Not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0		0.00
Spina bifida	5	0		12.83
Encephalocele	0	0		0.00
Microcephaly	1	1		5.13
Holoprosencephaly	1	0		2.57
Hydrocephaly	1	0		2.57
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	4	1		12.83
Tetralogy of Fallot	2	0		5.13
Hypoplastic left heart syndrome	2	0		5.13
Coarctation of aorta	2	0		5.13
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	8	0		20.52
Cleft lip with or without cleft palate	4	0		10.26
Oesophageal atresia/stenosis with or without fistula	0	0		0.00
Small intestine atresia/stenosis	0	0		0.00
Anorectal atresia/stenosis	1	0		2.57
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	12	0		30.79
Epispadias	0	0		0.00
Indeterminate sex	0	0		0.00
Renal agenesis	1	0		2.57
Cystic kidney	0	0		0.00
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	5	0		12.83
Total Limb reduction defects (include unspecified)	5	0		12.83
Transverse	nr	nr		nr
Preaxial	nr	nr		nr
Postaxial	nr	nr		nr
Intercalary	nr	nr		nr
Mixed	nr	nr		nr
Unspecified	nr	nr		nr
Diaphragmatic hernia	2	0		5.13
Omphalocele	2	0		5.13
Gastroschisis	0	0		0.00
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	0		2.57
Trisomy 18	0	0		0.00
Down syndrome, all ages (include age unknown)	5	0		12.83
<20	1	0		40.32
20-24	0	0		0.00
25-29	1	0		7.72
30-34	1	0		8.36
35-39	1	0		24.04
40-44	0	0		0.00
45+	1	0		3333.33
unknown	0	0		---

nr = not reported

Malta: MCAR, Previous years rates 1993 - 2007

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

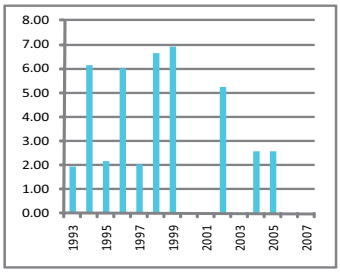
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births					**24,510**	**20,831**	**19,476**
Anencephaly					3.67	3.84	1.03
Spina bifida					7.34	5.28	7.19
Encephalocele					2.04	2.40	1.54
Microcephaly					4.08	3.36	4.11
Holoprosencephaly					0.82	1.44	0.51
Hydrocephaly					5.71	4.80	3.08
Anophthalmos					0.41	0.00	0.00
Microphthalmos					1.22	0.96	0.51
Unspecified Anophthalmos / Microphthalmos					0.00	0.00	0.00
Anotia					0.00	0.00	0.00
Microtia					0.00	0.00	0.00
Unspecified Anotia / Microtia					0.00	0.00	0.00
Transposition of great vessels					3.26	6.24	5.13
Tetralogy of Fallot					3.67	3.84	4.62
Hypoplastic left heart syndrome					1.22	2.88	3.08
Coarctation of aorta					6.12	5.28	4.11
Choanal atresia, bilateral					2.04	0.96	0.51
Cleft palate without cleft lip					14.69	12.96	12.32
Cleft lip with or without cleft palate					8.57	10.08	7.70
Oesophageal atresia / stenosis with or without fistula					1.63	1.92	2.57
Small intestine atresia / stenosis					1.22	1.92	1.54
Anorectal atresia / stenosis					4.08	5.76	3.08
Undescended testis (36 weeks of gestation or later)					nr	nr	nr
Hypospadias					15.10	40.80	33.37
Epispadias					1.63	0.00	0.00
Indeterminate sex					1.22	0.96	1.54
Renal agenesis					3.26	2.88	5.65
Cystic kidney					4.08	2.88	2.57
Bladder exstrophy					0.00	0.00	0.00
Polydactyly, preaxial					14.28	18.72	13.35
‘Total Limb reduction defects (include unspecified)					5.71	7.20	5.65
Transverse					nr	nr	nr
Preaxial					nr	nr	nr
Postaxial					nr	nr	nr
Intercalary					nr	nr	nr
Mixed					nr	nr	nr
Unspecified					nr	nr	nr
Diaphragmatic hernia					5.71	6.24	2.05
Omphalocele					2.86	1.44	2.57
Gastroschisis					1.22	0.96	1.03
Unspecified Omphalocele / Gastroschisis					0.00	0.00	0.00
Prune belly sequence					0.82	0.00	0.00
Trisomy 13					0.00	0.48	1.03
Trisomy 18					3.26	2.40	4.62
Down syndrome, all ages (include age unknown)					17.14	21.60	17.97
<20					0.00	16.88	8.65
20-24					0.00	0.00	2.87
25-29					3.50	11.61	4.29
30-34					18.49	20.01	18.00
35-39					58.42	65.79	64.48
40-44					166.11	166.05	153.85
45+					0.00	714.29	1000.00
unknown					---	---	---

nr = not reported

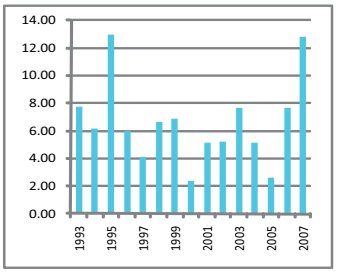
Malta: MCAR

'Time trends 1993-2007 (Birth prevalence rates per 10,000)

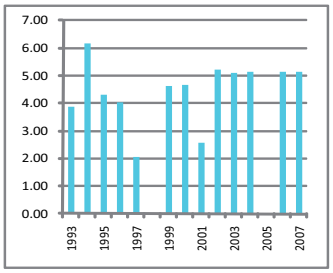
Anencephaly



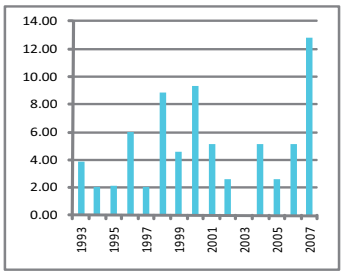
Spina Bifida



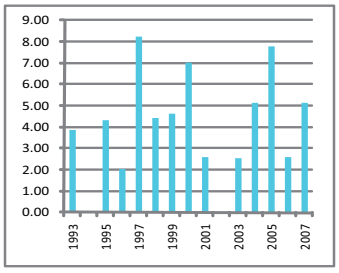
Microcephaly



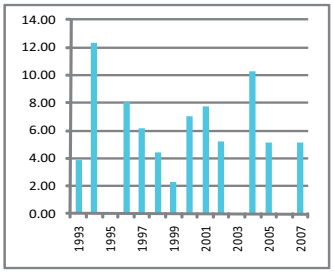
Transposition of great vessels



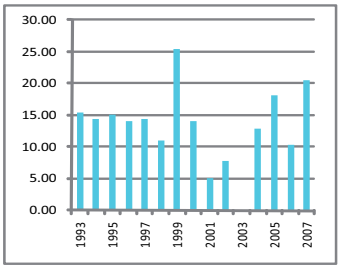
Tetralogy of Fallot



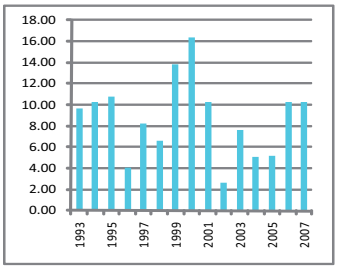
Coarctation of aorta



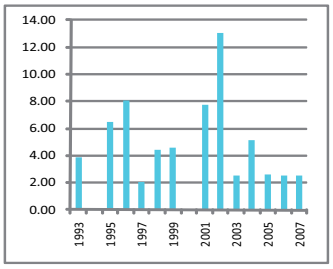
Cleft palate without cleft lip



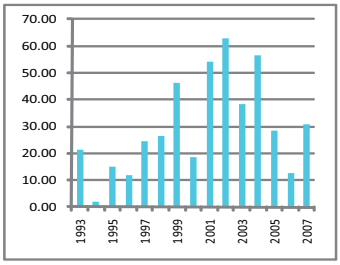
Cleft lip with or without cleft palate



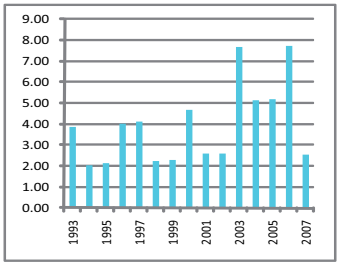
Anorectal atresia/stenosis



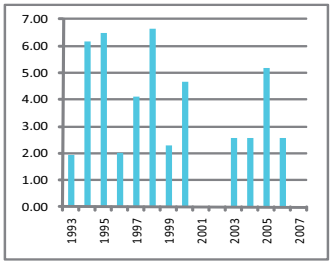
Hypospadias



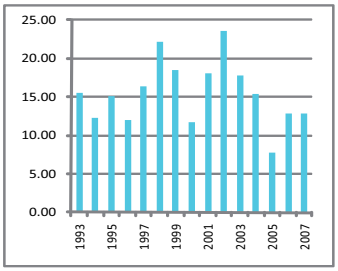
Renal agenesis



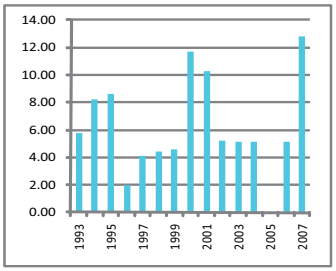
Cystic kidney



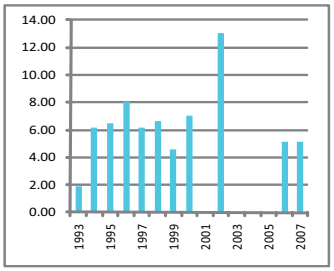
Polydactyly, preaxial



Limb reduction defects



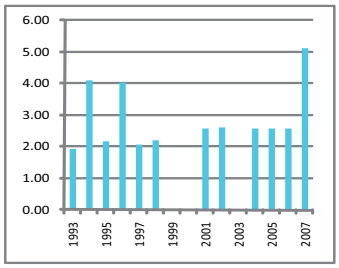
Diaphragmatic hernia



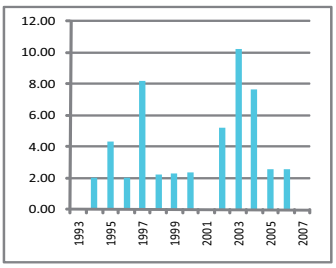
Note: L+S rates

Malta: MCAR

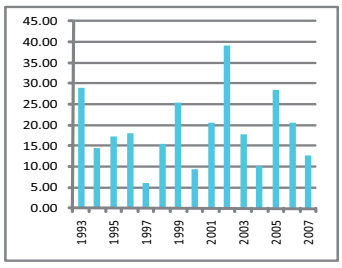
Omphalocele



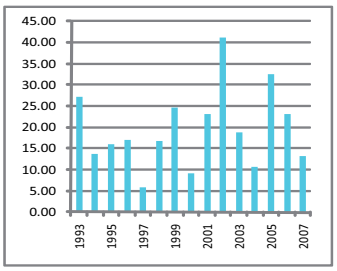
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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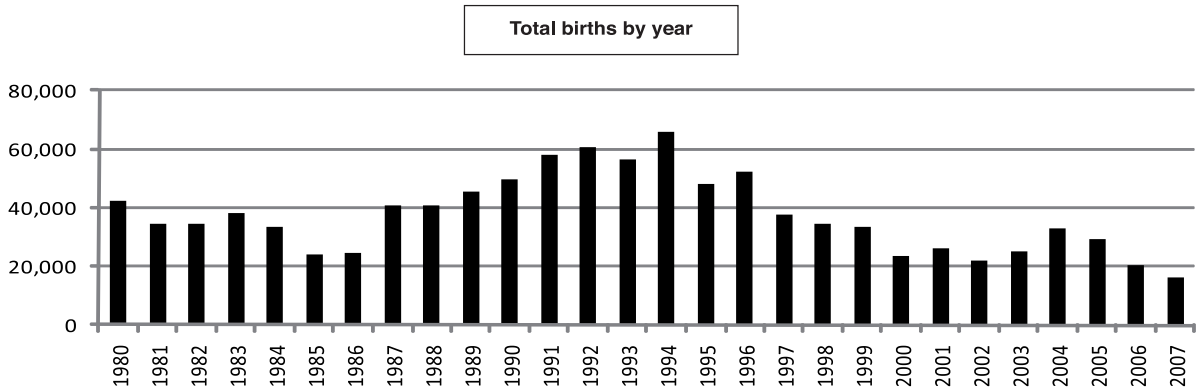
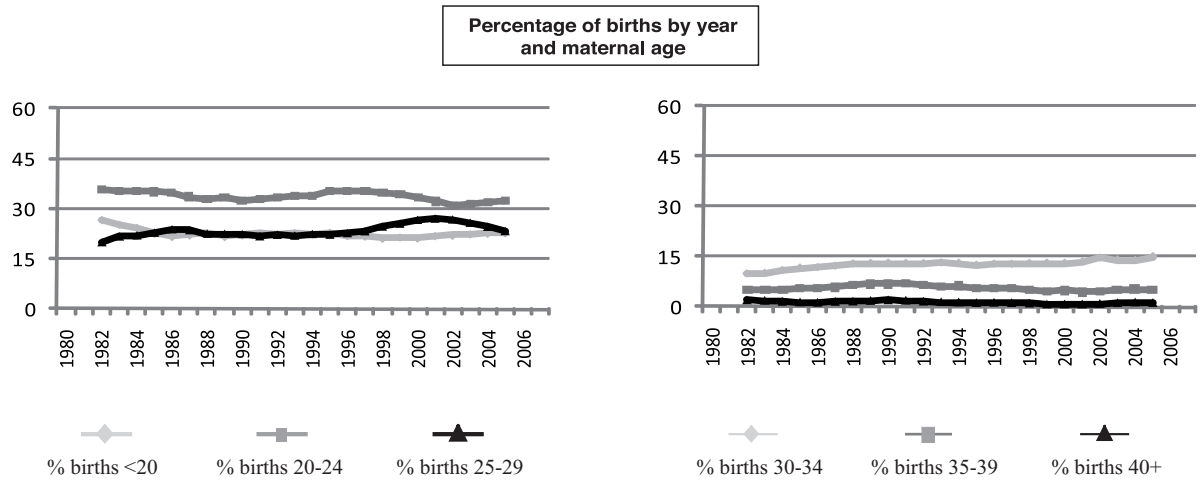
Vasco de Quiroga 15,Tlalpan, C.P.14000
Mexico DF, Mexico
Phone: 52-55-54870900 (ext 2514 and 2515)
Fax: 52-55-56556138
E-mail: osvaldo@servidor.unam.mx

Mexico: RYVEMCE





Mexico: RYVEMCE, 2007

Live births (LB)	16,008
Stillbirths (SB)	410
Total births	16,418
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	10		6.70
Spina bifida	13	0		7.92
Encephalocele	2	0		1.22
Microcephaly	0	0		0.00
Holoprosencephaly	3	0		1.83
Hydrocephaly	9	1		6.09
Anophthalmos	nr	nr		nr
Microphthalmos	nr	nr		nr
Unspecified Anophthalmos/Microphthalmos	3	1		2.44
Anotia	nr	nr		nr
Microtia	nr	nr		nr
Unspecified Anotia/Microtia	13	0		7.92
Transposition of great vessels	2	0		1.22
Tetralogy of Fallot	1	0		0.61
Hypoplastic left heart syndrome	0	0		0.00
Coarctation of aorta	0	0		0.00
Choanal atresia, bilateral	0	0		0.00
Cleft palate without cleft lip	5	0		3.05
Cleft lip with or without cleft palate	15	1		9.75
Oesophageal atresia/stenosis with or without fistula	6	1		4.26
Small intestine atresia/stenosis	6	0		3.65
Anorectal atresia/stenosis	5	1		3.65
Undescended testis (36 weeks of gestation or later)	nr	nr		nr
Hypospadias	7	0		4.26
Epispadias	0	0		0.00
Indeterminate sex	7	1		4.87
Renal agenesis	2	1		1.83
Cystic kidney	3	0		1.83
Bladder exstrophy	0	0		0.00
Polydactyly, preaxial	18	2		12.18
Total Limb reduction defects (include unspecified)	9	1		6.09
Transverse	5	1		3.65
Preaxial	0	0		0.00
Postaxial	0	0		0.00
Intercalary	0	0		0.00
Mixed	4	0		2.44
Unspecified	0	0		0.00
Diaphragmatic hernia	2	0		1.22
Omphalocele	2	0		1.22
Gastroschisis	11	1		7.31
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	0	0		0.00
Trisomy 13	1	0		0.61
Trisomy 18	1	0		0.61
Down syndrome, all ages (include age unknown)	18	1		11.57
<20	5	1		17.63
20-24	2	0		3.48
25-29	3	0		8.48
30-34	2	0		6.51
35-39	3	0		49.92
40-44	3	0		447.76
45+	0	0		nc
unknown	0	0		---

nr = not reported
nc = not calculable

Mexico: RYVEMCE, Previous years rates 1980 - 2007

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

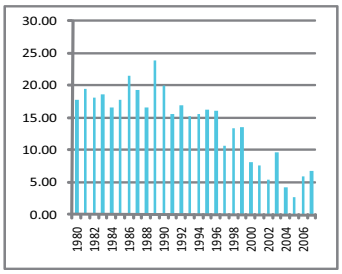
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**111,464**	**161,250**	**254,519**	**259,904**	**139,113**	**123,879**	
Anencephaly	18.39	18.73	18.43	15.04	10.21	5.57	
Spina bifida	12.29	13.46	15.91	15.08	11.21	7.51	
Encephalocele	3.50	3.53	2.32	2.50	1.87	1.53	
Microcephaly	2.33	2.67	2.36	1.65	1.73	2.18	
Holoprosencephaly	0.18	0.12	0.79	0.54	1.15	1.86	
Hydrocephaly	6.01	4.90	5.50	5.69	7.12	7.27	
Anophthalmos	2.42	2.36	1.89	1.31	1.51	2.06*	
Microphthalmos	nr	nr	nr	nr	nr	nr	
Unspecified Anophthalmos / Microphthalmos	nr	nr	nr	nr	nr	3.81*	
Anotia	6.82	6.14	6.99	5.73	8.55	9.40*	
Microtia	nr	nr	nr	nr	nr	nr	
Unspecified Anotia / Microtia	nr	nr	nr	nr	nr	8.44*	
Transposition of great vessels	0.09	0.06	0.08	0.15	0.36	0.48	
Tetralogy of Fallot	0.00	0.00	0.08	0.27	0.14	0.24	
Hypoplastic left heart syndrome	0.00	0.00	0.04	0.00	0.07	0.24	
Coarctation of aorta	0.09	0.00	0.04	0.12	0.00	0.08	
Choanal atresia, bilateral	0.18	0.25	0.39	0.54	0.07	0.24	
Cleft palate without cleft lip	3.23	3.72	3.77	3.04	2.52	3.31	
Cleft lip with or without cleft palate	12.83	12.53	12.57	12.27	14.02	14.53	
Oesophageal atresia / stenosis with or without fistula	1.08	1.36	2.51	1.96	2.30	3.47	
Small intestine atresia / stenosis	0.81	0.62	1.22	1.31	1.44	2.66	
Anorectal atresia / stenosis	3.68	4.40	4.91	4.69	4.60	4.92	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	nr	
Hypospadias	3.95	4.28	4.68	4.66	3.09	4.36	
Epispadias	nr	nr	nr	nr	nr	0.10*	
Indeterminate sex	1.26	2.17	2.40	2.50	1.87	2.91	
Renal agenesis	0.36	0.31	0.55	0.54	0.65	0.89	
Cystic kidney	0.27	0.56	0.47	0.85	1.80	1.29	
Bladder exstrophy	0.27	0.62	0.47	0.31	0.58	0.08	
Polydactyly, preaxial	11.84	12.28	13.79	11.66	13.23	11.14	
‘Total Limb reduction defects (include unspecified)	5.56	6.45	6.68	5.39	5.82	6.94	
Transverse	nr	nr	nr	nr	3.64*	3.39	
Preaxial	nr	nr	nr	nr	0.98*	1.13	
Postaxial	nr	nr	nr	nr	0.42*	0.40	
Intercalary	nr	nr	nr	nr	0.42*	0.40	
Mixed	nr	nr	nr	nr	0.42*	1.29	
Unspecified	nr	nr	nr	nr	0.00*	0.32	
Diaphragmatic hernia	0.54	0.68	0.90	1.12	1.01	1.29	
Omphalocele	1.70	1.55	1.57	1.77	1.65	2.10	
Gastroschisis	0.72	0.93	1.53	2.39	4.31	5.41	
Unspecified Omphalocele / Gastroschisis	nr	nr	nr	nr	nr	nr	
Prune belly sequence	1.08	1.24	1.34	0.58	0.86	0.40	
Trisomy 13	0.45	0.25	0.24	0.12	0.29	0.65	
Trisomy 18	0.90	0.43	0.51	0.19	0.14	0.65	
Down syndrome, all ages (include age unknown)	13.82	12.22	13.79	13.35	11.14	11.87	
<20	6.71	6.92	11.41	7.17	4.38	9.47	
20-24	7.66	4.40	8.35	6.98	4.28	7.32	
25-29	9.30	5.50	10.74	11.46	5.46	6.90	
30-34	23.61	16.30	13.35	12.55	16.84	9.24	
35-39	48.40	48.69	32.12	49.07	54.50	53.08	
40-44	107.11	202.51	91.38	200.68	310.88	125.09	
45+	82.99	277.77*	165.61	192.92*	169.49*	123.45*	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

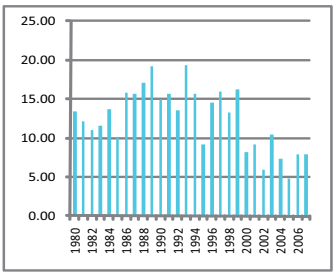
Mexico: RYVEMCE

'Time trends 1980-2007 (Birth prevalence rates per 10,000)

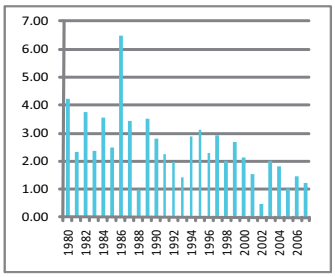
Anencephaly



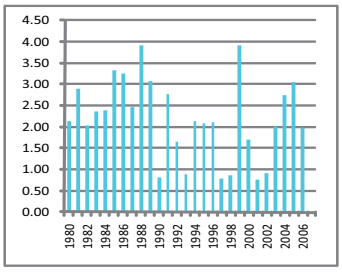
Spina Bifida



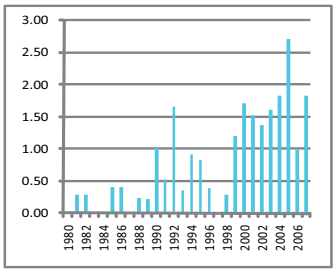
Encephalocele



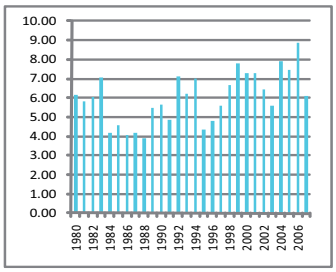
Microcephaly



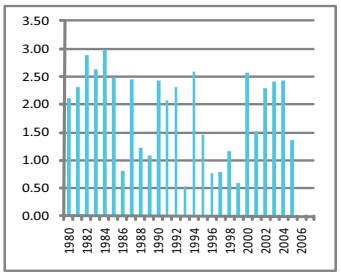
Holoprosencephaly



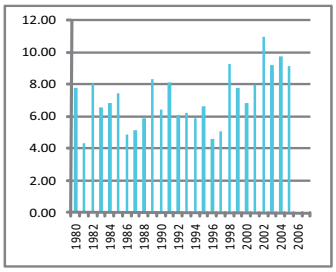
Hydrocephaly



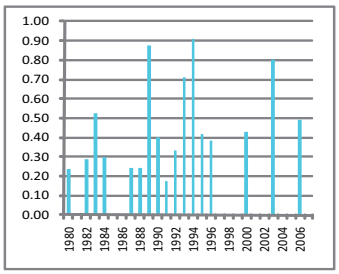
Anophthalmos



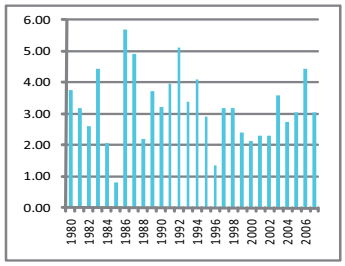
Anotia



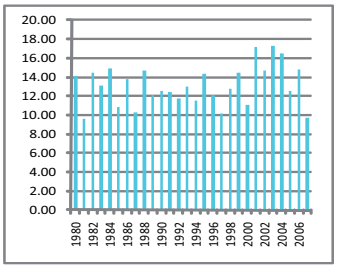
Choanal atresia, bilateral



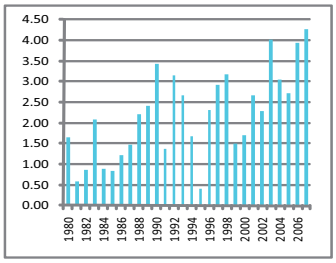
Cleft palate without cleft lip



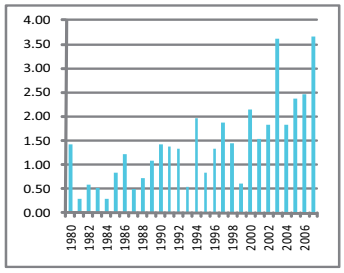
Cleft lip with or without cleft palate



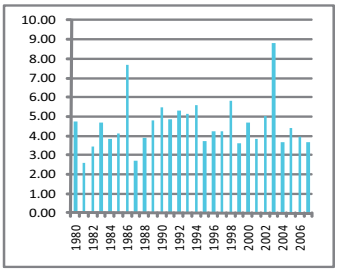
Oesophageal atresia/stenosis with or without fistula



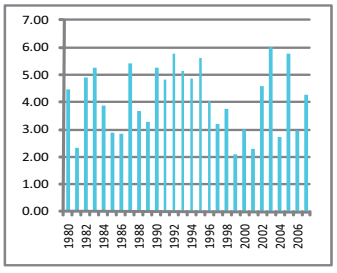
Small intestine atresia/stenosis



Anorectal atresia/stenosis



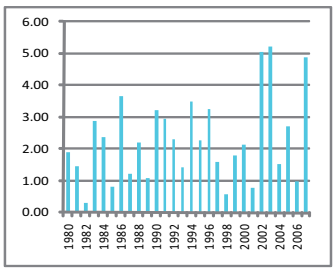
Hypospadias



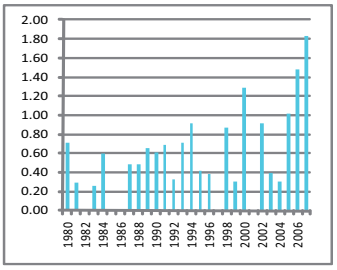
Note: L+S rates

Mexico: RYVEMCE

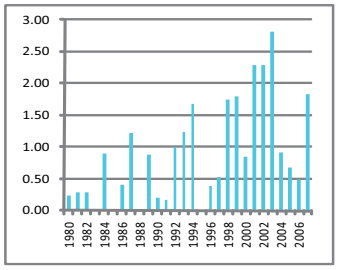
Indeterminate sex



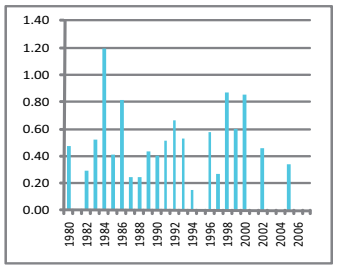
Renal agenesis



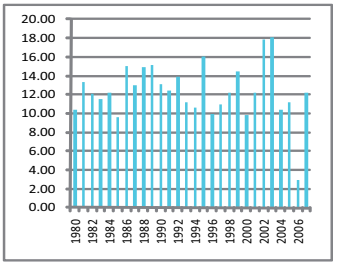
Cystic kidney



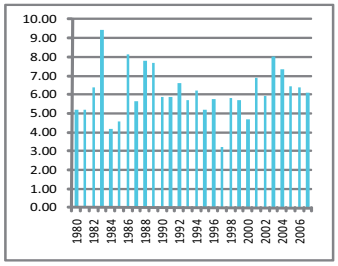
Bladder exstrophy



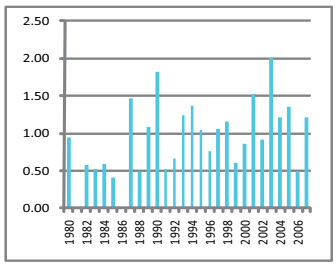
Polydactyly, preaxial



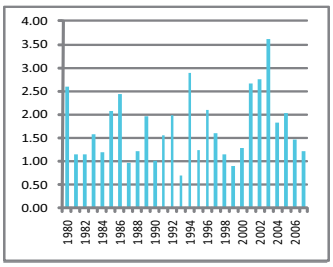
Limb reduction defects



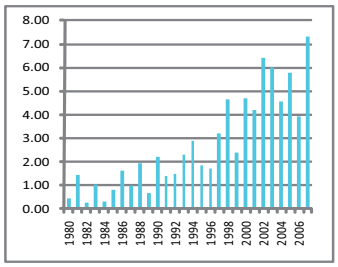
Diaphragmatic hernia



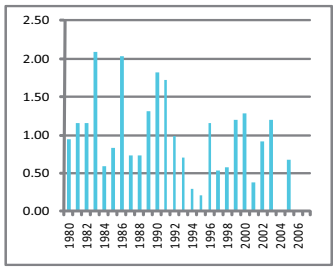
Omphalocele



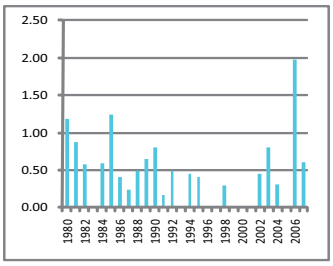
Gastroschisis



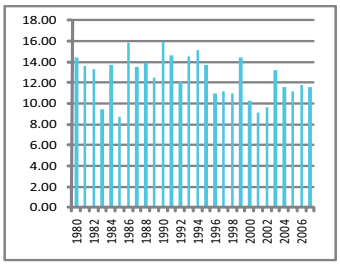
Prune belly sequence



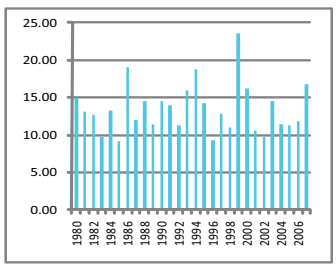
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

New Zealand

New Zealand Birth Monitoring Defects Programme

History:
The Programme began in 1975 and became a full member of the ICBDSR in 1979.

Size and coverage:
The Programme covers all livebirths (approximately 58,000 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 stillbirths are retrospectively added to the database together with additional cases derived from the national perinatal and mortality databases. In late 1995 the definition of stillbirth was changed from 28 weeks completed gestation to 20 weeks or more gestation and/or 400g birthweight.

Legislation and funding:
The Programme is run and funded by the Centre for Public Health Research, Massey University.

Sources of ascertainment:
Ascertainment is from discharge records of publicly funded hospitals and stillbirth notification forms. Data on voluntary terminations of pregnancy are being added to the database.

Exposure information:
No exposure information are currently available, but attempts are being made to obtain such data as well as increase the level of ascertainment.

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

Addresses and Staff:
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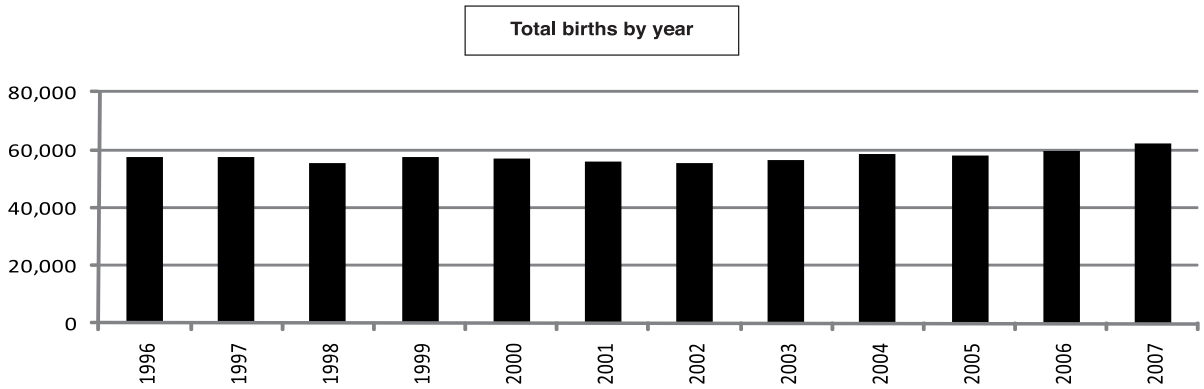
New Zealand Birth Defects Monitoring Programme
Centre for Public Health Research
Massey University
PO Box 756
Wellington 6140 - New Zealand
Phone: 64-4-8015799
Fax: 64-4-3800600
E-mail: b.borman@massey.ac.nz

New Zealand


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

New Zealand: 2007

Live births (LB)	62,362
Stillbirths (SB)	nr
Total births	62,362
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	0.16
Spina bifida	8	nr	nr	1.28
Encephalocele	4	nr	nr	0.64
Microcephaly	11	nr	nr	1.76
Holoprosencephaly	nr	nr	nr	nr
Hydrocephaly	23	nr	nr	3.69
Anophthalmos	2	nr	nr	0.32
Microphthalmos	3	nr	nr	0.48
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	nr	nr	nr	nr
Microtia	nr	nr	nr	nr
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	24	nr	nr	3.85
Tetralogy of Fallot	23	nr	nr	3.69
Hypoplastic left heart syndrome	4	nr	nr	0.64
Coarctation of aorta	11	nr	nr	1.76
Choanal atresia, bilateral	5	nr	nr	0.80
Cleft palate without cleft lip	45	nr	nr	7.22
Cleft lip with or without cleft palate	43	nr	nr	6.90
Oesophageal atresia/stenosis with or without fistula	nr	nr	nr	nr
Small intestine atresia/stenosis	12	nr	nr	1.92
Anorectal atresia/stenosis	18	nr	nr	2.89
Undescended testis (36 weeks of gestation or later)	315	nr	nr	50.51
Hypospadias	191	nr	nr	30.63
Epispadias	nr	nr	nr	nr
Indeterminate sex	4	nr	nr	0.64
Renal agenesis	16	nr	nr	2.57
Cystic kidney	33	nr	nr	5.29
Bladder exstrophy	1	nr	nr	0.16
Polydactyly, preaxial	199	nr	nr	31.91
Total Limb reduction defects (include unspecified)	11	nr	nr	1.76
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	13	nr	nr	2.08
Omphalocele	26	nr	nr	4.17
Gastroschisis	nr	nr	nr	nr
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	nr	nr	nr	nr
Trisomy 13	3	nr	nr	0.48
Trisomy 18	6	nr	nr	0.96
Down syndrome, all ages (include age unknown)	62	nr	nr	9.94
<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 - 2007

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

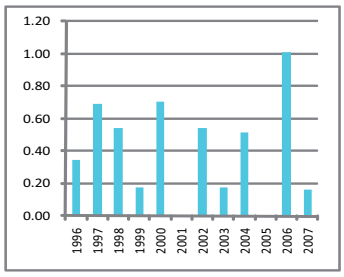
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**144,172**	**258,923**	**289,826**	**291,920**	**281,443**	**295,066**	
Anencephaly	6.59	3.36	1.21	0.58	0.39	0.37	
Spina bifida	11.24	9.15	3.97	3.70	2.66	1.93	
Encephalocele	nr	0.70	0.73*	0.40*	0.32	0.47	
Microcephaly	nr	nr	nr	2.43*	2.98	2.68	
Holoprosencephaly	nr	nr	nr	nr	nr	nr	
Hydrocephaly	4.92	3.51	2.42	3.56	3.91	3.29	
Anophthalmos	nr	nr	nr	0.00*	0.04	0.13*	
Microphthalmos	nr	nr	nr	0.43*	0.89	0.64*	
Unspecified Anophthalmos / Microphthalmos	nr	nr	nr	0.00*	0.00	0.13*	
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	0.18*	0.91*	4.86*	5.12	4.51	
Tetralogy of Fallot	nr	nr	nr	nr	4.19	4.54	
Hypoplastic left heart syndrome	nr	0.91*	0.73*	1.50*	1.28	1.02	
Coarctation of aorta	nr	nr	nr	nr	2.66	2.81	
Choanal atresia, bilateral	nr	nr	nr	0.52	1.35	0.92	
Cleft palate without cleft lip	6.17	7.34	5.69	5.86	9.95	9.22	
Cleft lip with or without cleft palate	9.29	8.57	6.56	3.29	5.12	6.91	
Oesophageal atresia / stenosis with or without fistula	1.66	1.85	1.79	2.67	1.53	1.89*	
Small intestine atresia / stenosis	nr	nr	nr	1.82*	1.77*	2.27	
Anorectal atresia / stenosis	2.43	2.59	2.07	2.91	2.56	2.37	
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	47.80*	75.33	65.65	
Hypospadias	11.38	15.10	11.21	15.17*	27.96	29.28	
Epispadias	nr	nr	nr	nr	nr	nr	
Indeterminate sex	nr	nr	nr	0.17*	0.57	0.81	
Renal agenesis	nr	0.24*	0.73*	3.29*	3.20	3.08	
Cystic kidney	nr	nr	nr	5.90*	5.83	5.32	
Bladder exstrophy	nr	nr	nr	0.43*	0.35*	0.14	
Polydactyly, preaxial	nr	nr	nr	5.99*	10.39*	14.67	
'Total Limb reduction defects (include unspecified)	3.61	3.48	3.00	1.88	2.84	2.47	
Transverse	nr	nr	nr	nr	nr	nr	
Preaxial	nr	nr	nr	nr	nr	nr	
Postaxial	nr	nr	nr	nr	nr	nr	
Intercalary	nr	nr	nr	nr	nr	nr	
Mixed	nr	nr	nr	nr	nr	nr	
Unspecified	nr	nr	nr	nr	nr	2.01*	
Diaphragmatic hernia	nr	1.51	1.46*	nr	2.45	2.33*	
Omphalocele	2.45	2.16	1.00	4.45*	nr	4.17*	
Gastroschisis	0.00	0.42	1.09*	nr	nr	nr	
Unspecified Omphalocele / Gastroschisis	0.00	0.23	0.36*	nr	nr	5.01*	
Prune belly sequence	nr	nr	nr	nr	nr	nr	
Trisomy 13	nr	nr	nr	0.52*	0.39	0.58	
Trisomy 18	nr	nr	nr	0.95*	1.24	1.08	
Down syndrome, all ages (include age unknown)	8.05	9.46	9.56	9.37*	12.61	10.17	
<20	3.60	7.08	nr	nr	nr	nr	
20-24	5.12	3.64	nr	nr	nr	nr	
25-29	7.92	8.88	nr	nr	nr	nr	
30-34	9.11	9.67	nr	nr	nr	nr	
35-39	27.31	35.07	nr	nr	nr	nr	
40-44	63.64	189.06	nr	nr	nr	nr	
45+	104.17	172.41	nr	nr	nr	nr	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

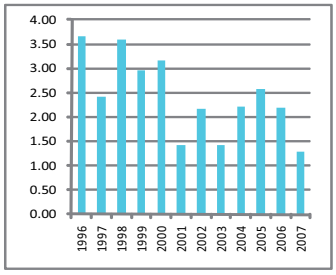
New Zealand

Time trends 1980-2007 (Birth prevalence rates per 10,000)

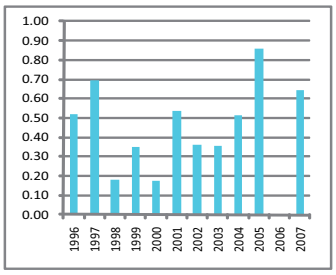
Anencephaly



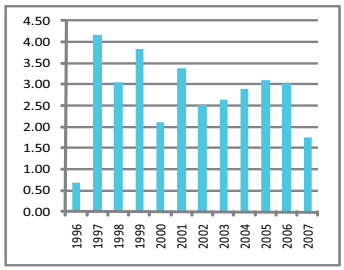
Spina Bifida



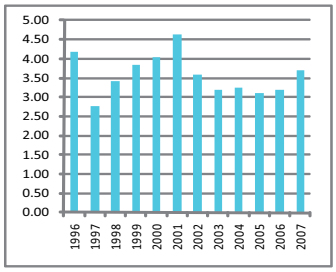
Encephalocele



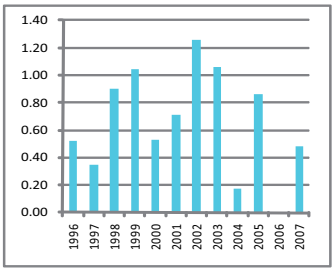
Microcephaly



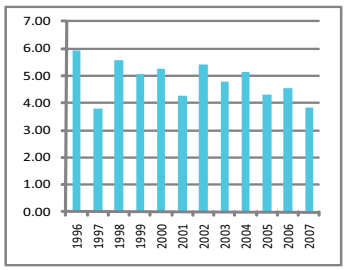
Hydrocephaly



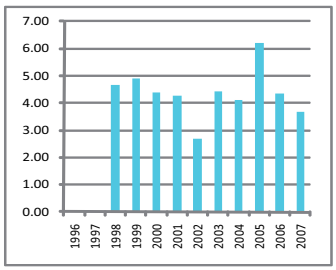
Microphthalmos



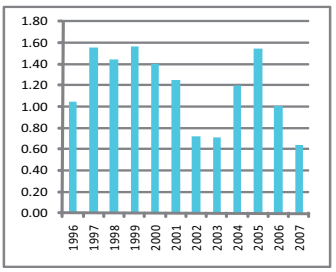
Transposition of great vessels



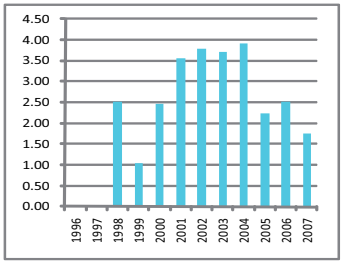
Tetralogy of Fallot



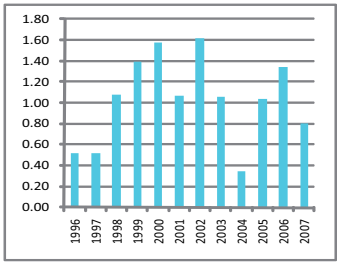
Hypoplastic left heart syndrome



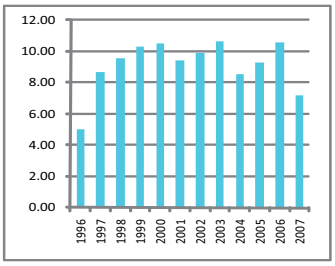
Coarctation of aorta



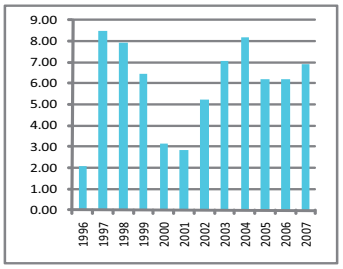
Choanal atresia, bilateral



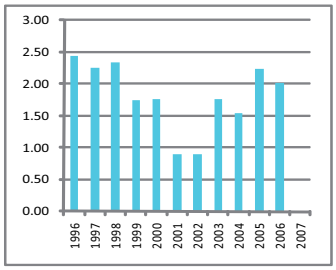
Cleft palate without cleft lip



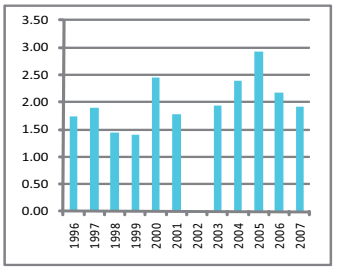
Cleft lip with or without cleft palate



Oesophageal atresia/stenosis with or without fistula



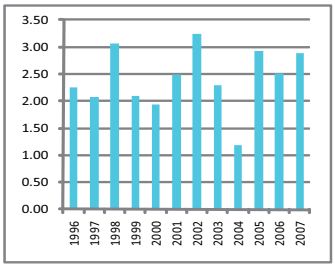
Small intestine atresia/stenosis



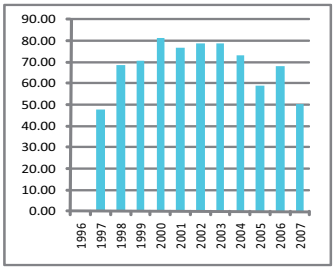
Note: L+S rates

New Zealand

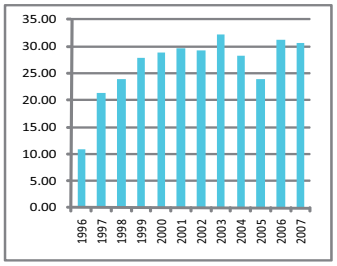
Anorectal atresia/stenosis



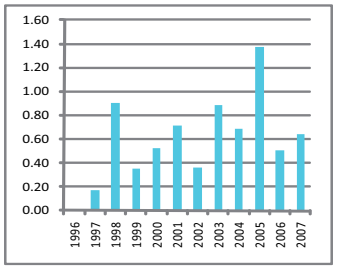
Undescended testis



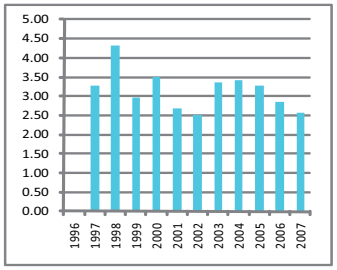
Hypospadias



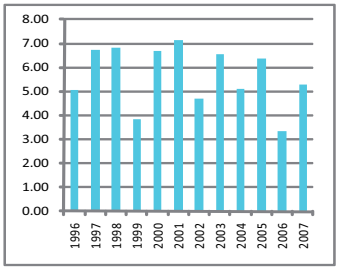
Indeterminate sex



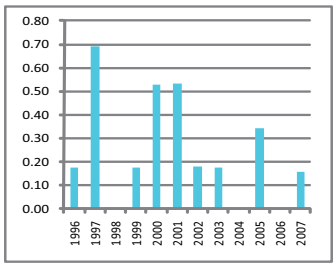
Renal agenesis



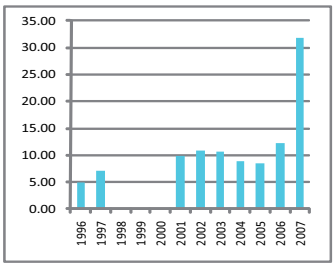
Cystic kidney



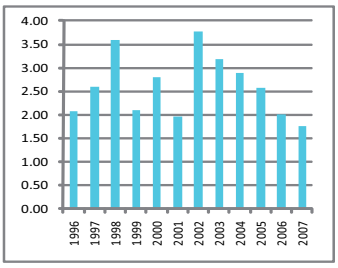
Limb reduction defects



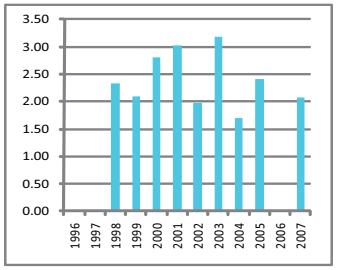
Limb reduction defects - transverse



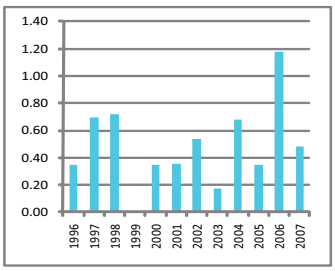
Limb reduction defects - preaxial



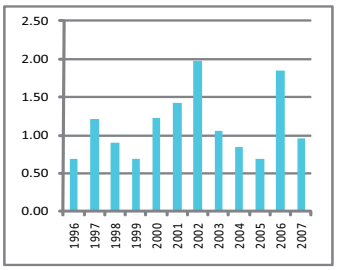
Diaphragmatic hernia



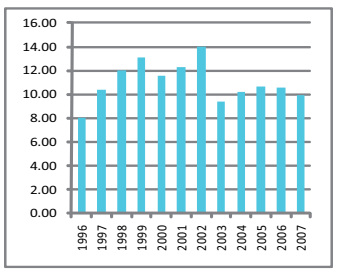
Trisomy 13



Trisomy 18



Down Syndrome



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).

Addresses and Staff:
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University of Groningen
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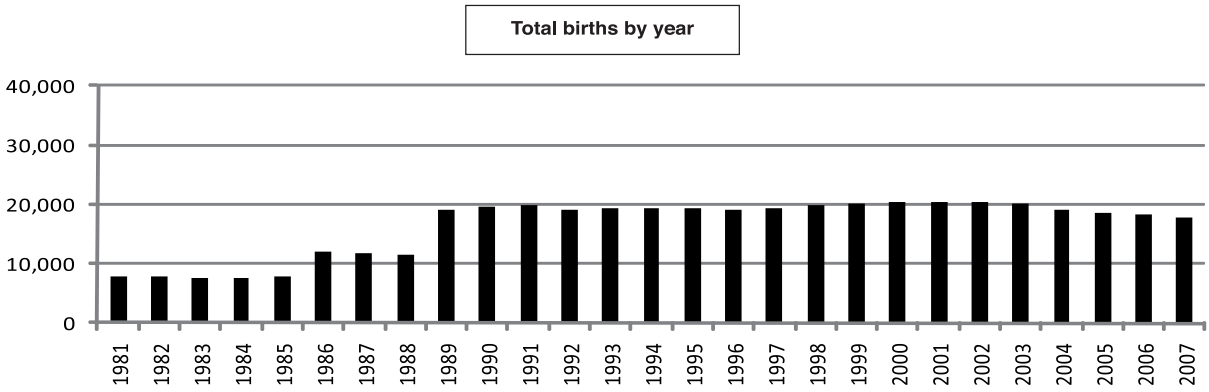
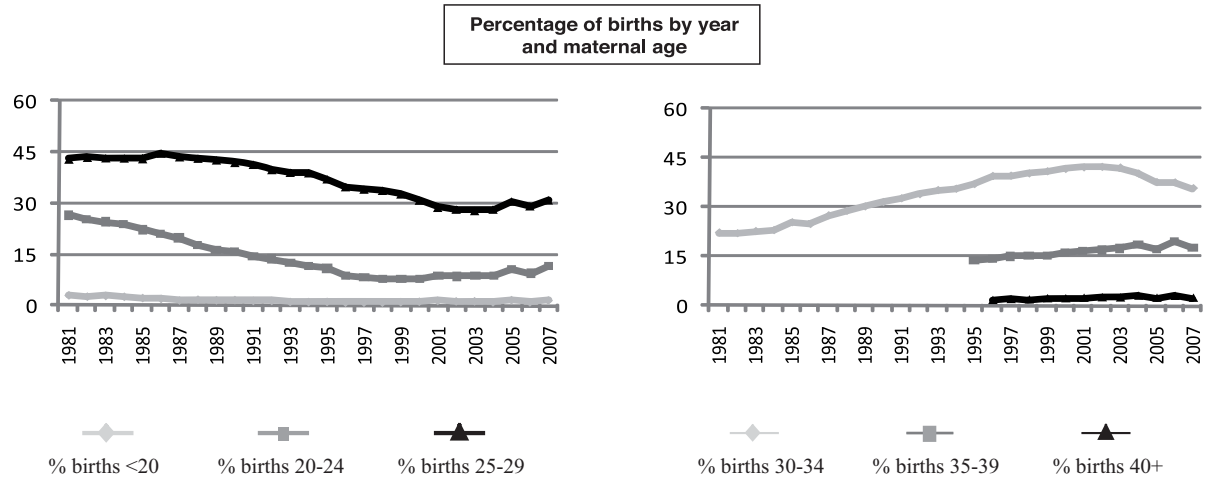
9700 RB Groningen, The Netherlands
Phone: 31-50-3617110 / 3617115
Fax: 31-50-3617232
E-mail: m.k.bakker@medgen.umcg.nl

Hermien de Walle
E-mail: h.e.k.de.Walle@medgen.umcg.nl

Website: www.eurocatnederland.nl

Northern Netherlands





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	7	70.0	Cystic kidney	3	9.7
Spina bifida	9	31.0	Limb reduction defects	1	3.2
Encephalocele	2	100.0	Diaphragmatic hernia	1	14.3
Holoprosencephaly	1	33.3	Omphalocele	5	50.0
Hydrocephaly	6	28.6	Gastroschisis	2	50.0
Hypoplastic left heart syndrome	4	25.0	Trisomy 13	10	90.9
Cleft palate without cleft lip	5	11.9	Trisomy 18	24	60.0
Cleft lip with or without cleft palate	6	7.8	Down syndrome	28	31.8
Renal agenesis	5	22.7			

Total ToPs with births defects = 120 (Ratio ToPs/Births: 2.21 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Northern Netherlands: 2007

Live births (LB)	17,594
Stillbirths (SB)	84
Total births	17,678
Number of terminations of pregnancy (ToP) for birth defects	51

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	2	1.70
Spina bifida	6	0	3	5.09
Encephalocele	0	0	0	0.00
Microcephaly	4	0	0	2.26
Holoprosencephaly	0	0	0	0.00
Hydrocephaly	3	0	4	3.96
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	1.13
Microtia	2	0	0	1.13
Unspecified Anotia/Microtia	1	0	0	0.57
Transposition of great vessels	8	0	2	5.66
Tetralogy of Fallot	2	0	0	1.13
Hypoplastic left heart syndrome	3	0	2	2.83
Coarctation of aorta	7	0	1	4.53
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	11	0	1	6.79
Cleft lip with or without cleft palate	22	0	3	14.14
Oesophageal atresia/stenosis with or without fistula	5	0	0	2.83
Small intestine atresia/stenosis	2	0	0	1.13
Anorectal atresia/stenosis	6	0	0	3.39
Undescended testis (36 weeks of gestation or later)	0	0	0	0.00
Hypospadias	38	0	0	21.50
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	0.57
Renal agenesis	5	0	1	3.39
Cystic kidney	5	0	0	2.83
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	1	0	0	0.57
Total Limb reduction defects (include unspecified)	8	1	1	5.66
Transverse	6	0	0	3.39
Preaxial	0	0	0	0.00
Postaxial	1	0	0	0.57
Intercalary	0	0	0	0.00
Mixed	0	0	0	0.00
Unspecified	0	0	0	0.00
Diaphragmatic hernia	1	0	1	1.13
Omphalocele	1	0	2	1.70
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	7	3.96
Trisomy 18	1	1	10	6.79
Down syndrome, all ages (include age unknown)	20	0	7	15.27
<20	0	0	0	0.00
20-24	0	0	1	4.94
25-29	3	0	0	5.47
30-34	9	0	2	17.39
35-39	6	0	4	31.89
40-44	1	0	0	24.27
45+	1	0	0	1,250.00
unknown	0	0	0	---

Northern Netherlands: Previous years rates 1981 - 2007

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

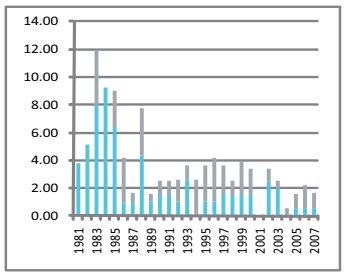
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**15,608**	**46,676**	**89,316**	**96,465**	**101,588**	**93,512**	
Anencephaly	4.48	6.43	3.02	3.52	2.66	1.71	
Spina bifida	5.77	4.71	9.18	5.08	4.53	5.24	
Encephalocele	1.92	1.29	1.12	0.83	0.89	0.53	
Microcephaly	4.48	4.93	3.36	4.35	4.13	2.57	
Holoprosencephaly	1.92	1.50	0.67	0.62	1.48	0.75	
Hydrocephaly	2.56	4.93	3.02	4.35	3.64	3.42	
Anophthalmos	0.00	0.21	0.34	0.31	0.30	0.21	
Microphthalmos	2.56	1.29	1.57	2.18	1.18	0.75	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	3.20	1.50	0.78	1.04	0.89	1.07	
Microtia	0.64	0.86	0.90	0.93	0.89	0.75	
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.11	
Transposition of great vessels	3.20	3.00	3.69	4.98	3.74	3.96	
Tetralogy of Fallot	5.13	3.00	4.03	2.80	3.35	3.74	
Hypoplastic left heart syndrome	2.56	2.57	2.46	1.87	2.85	2.78	
Coarctation of aorta	7.05	5.14	5.60	6.01	4.53	5.24	
Choanal atresia, bilateral	0.64	0.43	0.45	0.62	0.59	0.43	
Cleft palate without cleft lip	8.33	6.43	6.83	7.36	8.56	7.81	
Cleft lip with or without cleft palate	17.30	15.21	15.00	15.24	13.98	14.54	
Oesophageal atresia / stenosis with or without fistula	3.20	2.79	2.58	3.84	3.15	3.74	
Small intestine atresia / stenosis	3.84	2.57	2.69	2.59	2.07	1.28	
Anorectal atresia / stenosis	1.92	3.00	3.69	2.59	4.33	3.32	
Undescended testis (36 weeks of gestation or later)	2.59	2.14	1.68	1.55	1.57	0.43	
Hypospadias	18.58	11.35	10.19	11.20	16.64	22.03	
Epispadias	0.00	0.43	0.56	0.62	0.49	0.43	
Indeterminate sex	0.00	0.21	0.34	0.21	0.39	0.53	
Renal agenesis	2.56	4.93	4.25	4.77	5.22	3.74	
Cystic kidney	2.56	2.79	5.82	5.08	3.35	5.35	
Bladder exstrophy	0.00	0.21	0.34	0.00	0.20	0.32	
Polydactyly, preaxial	1.28	1.71	1.90	2.38	1.87	0.64	
‘Total Limb reduction defects (include unspecified)	8.97	6.00	6.72	5.91	5.81	6.31	
Transverse	5.77	3.43	3.69	3.63	3.74	4.06	
Preaxial	1.92	0.64	0.78	0.83	0.59	1.28	
Postaxial	0.64	1.29	1.23	1.14	1.38	1.82	
Intercalary	0.00	0.00	0.22	0.10	0.20	0.32	
Mixed	0.00	0.43	0.22	0.31	0.79	2.25	
Unspecified	0.64	0.86	0.56	0.31	0.10	0.11	
Diaphragmatic hernia	1.92	2.79	2.46	3.52	2.07	1.92	
Omphalocele	1.28	2.14	3.13	2.80	1.77	2.03	
Gastroschisis	0.64	1.29	0.45	0.62	1.08	0.86	
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.00	0.00	0.00	
Prune belly sequence	0.64	0.21	0.45	0.41	0.39	0.11	
Trisomy 13	0.00	1.07	1.46	1.14	0.98	1.71	
Trisomy 18	3.20	1.71	2.58	2.49	3.45	6.42	
Down syndrome, all ages (include age unknown)	10.89	13.71	14.33	15.34	15.65	15.83	
<20	0.00	0.00	0.00	0.00	0.00	0.00	
20-24	7.43	6.83	10.17	6.98	1.21	7.68	
25-29	4.44	10.28	9.91	5.62	10.51	7.65	
30-34	11.58	12.89	13.44	13.87	9.26	11.88	
35-39	54.88	48.24	32.97	42.33	34.50	30.77	
40-44	nr	nr	nr	nr	121.62	100.25	
45+	nr	nr	nr	nr	277.78	135.14	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

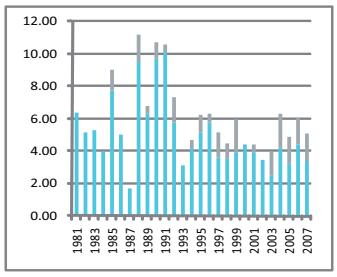
Northern Netherlands

'Time trends 1981-2007 (Birth prevalence rates per 10,000)

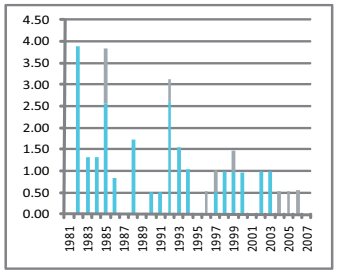
Anencephaly



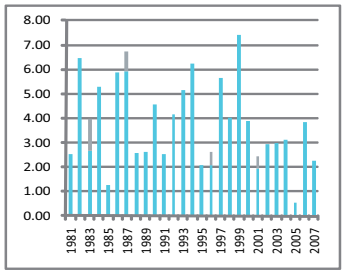
Spina Bifida



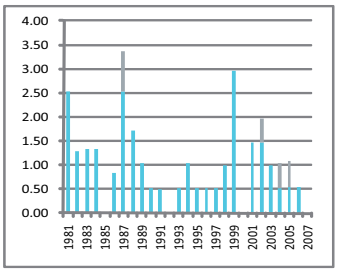
Encephalocele



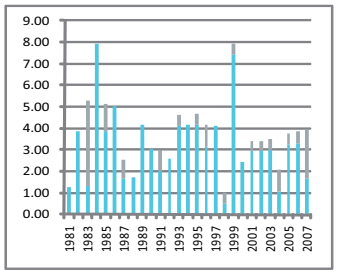
Microcephaly



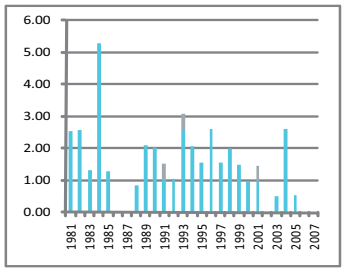
Holoprosencephaly



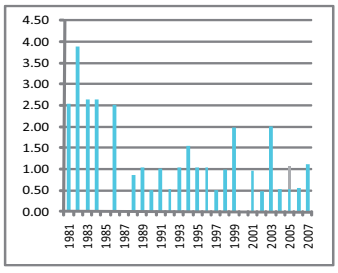
Hydrocephaly



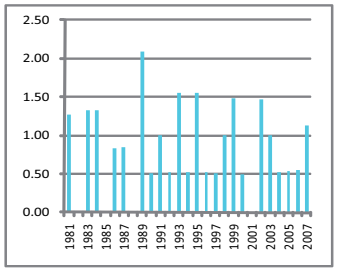
Microphthalmos



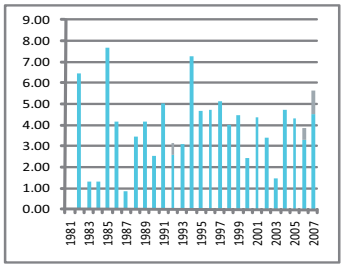
Anotia



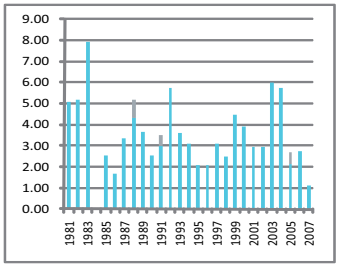
Microtia



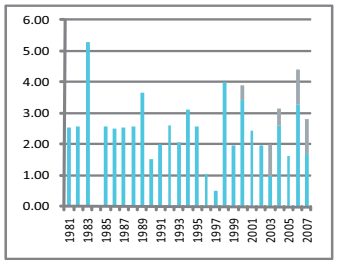
Transposition of great vessels



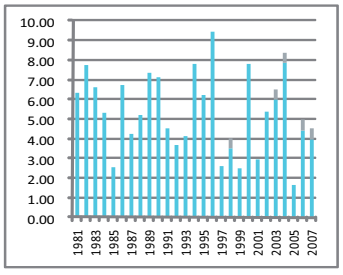
Tetralogy of Fallot



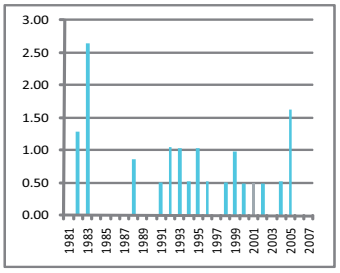
Hypoplastic left heart syndrome



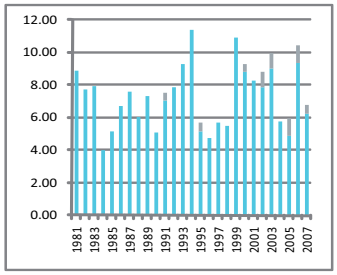
Coarctation of aorta



Choanal atresia, bilateral



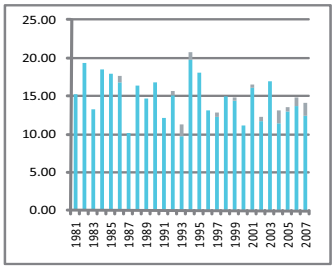
Cleft palate without cleft lip



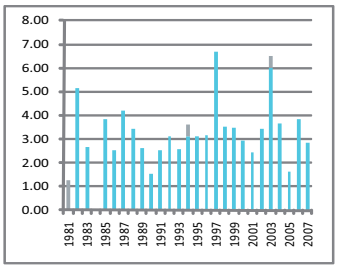
Note: L+S rates, ToP rates

Northern Netherlands

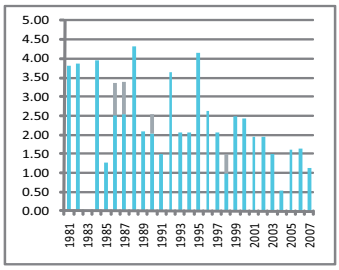
Cleft lip with or without cleft palate



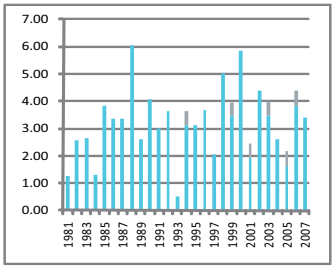
Oesophageal atresia/stenosis with or without fistula



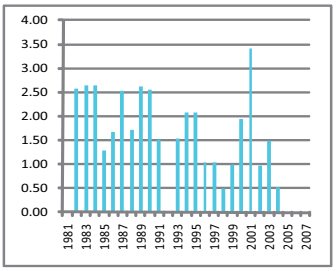
Small intestine atresia/stenosis



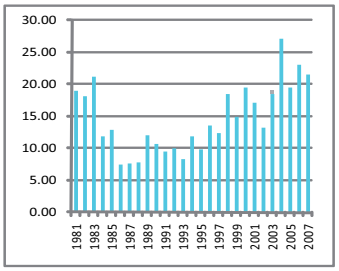
Anorectal atresia/stenosis



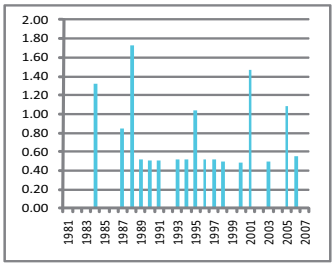
Undescended testis



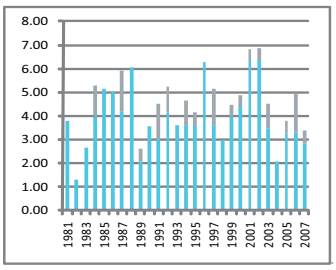
Hypospadias



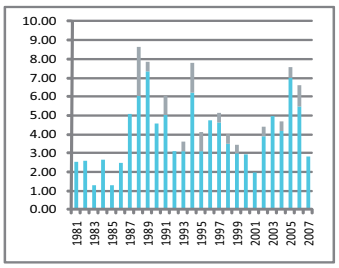
Epispadias



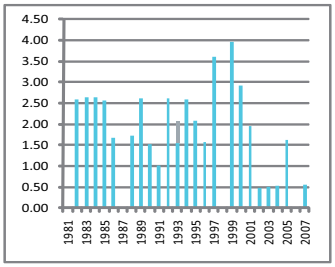
Renal agenesis



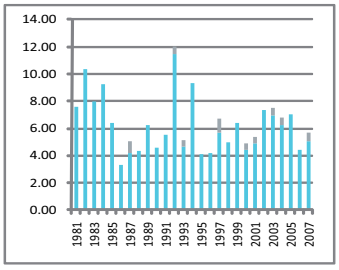
Cystic kidney



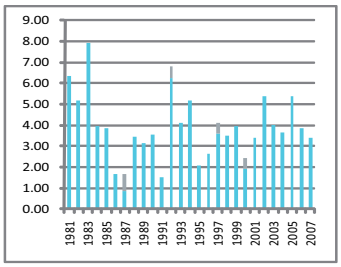
Polydactyly, preaxial



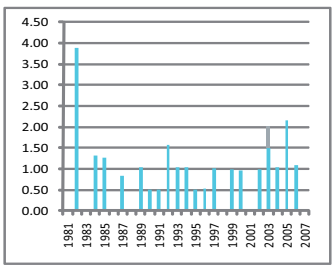
Limb reduction defects



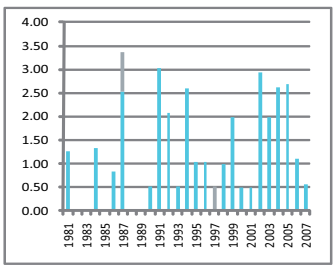
Limb reduction defects - transverse



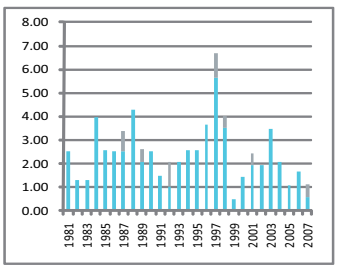
Limb reduction defects - preaxial



Limb reduction defects - postaxial



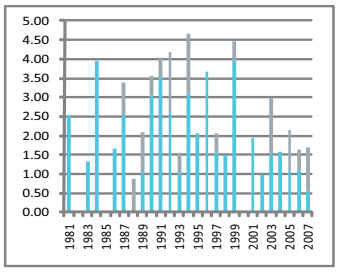
Diaphragmatic hernia



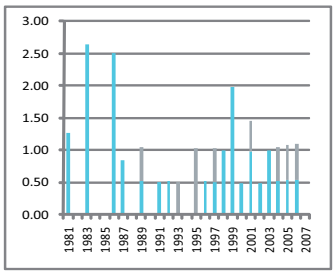
Note: L+S rates, ToP rates

Northern Netherlands

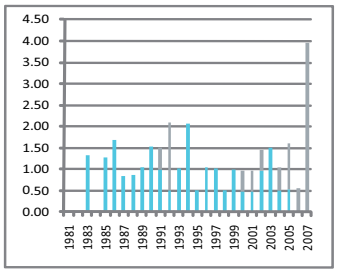
Omphalocele



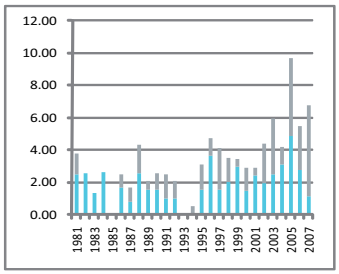
Gastroschisis



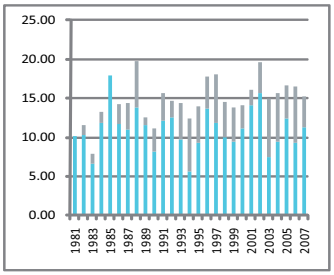
Trisomy 13



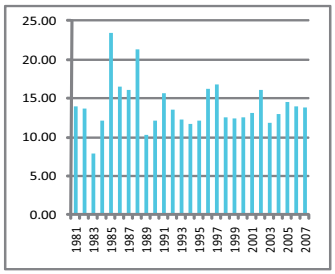
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Norway: MBRN

Medical Birth Registry of Norway

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

Size and coverage:
The Programme covers all births in Norway, approximately 60,000 annual births.
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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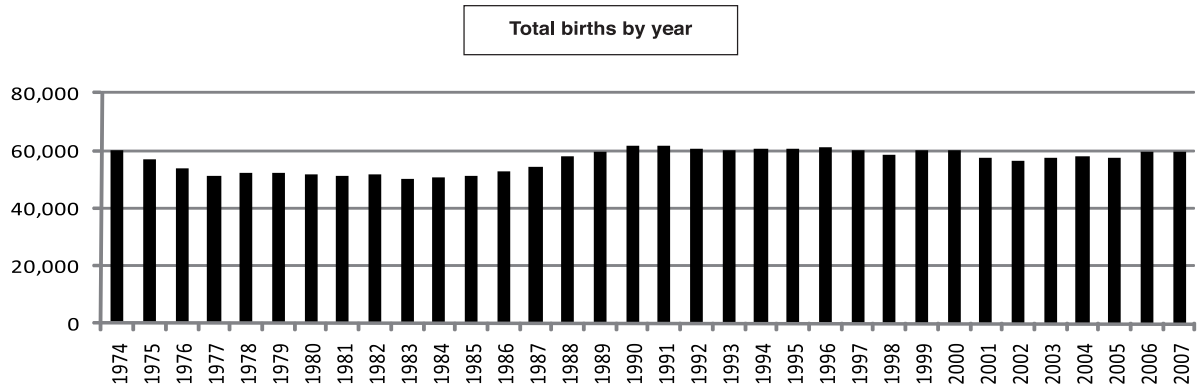
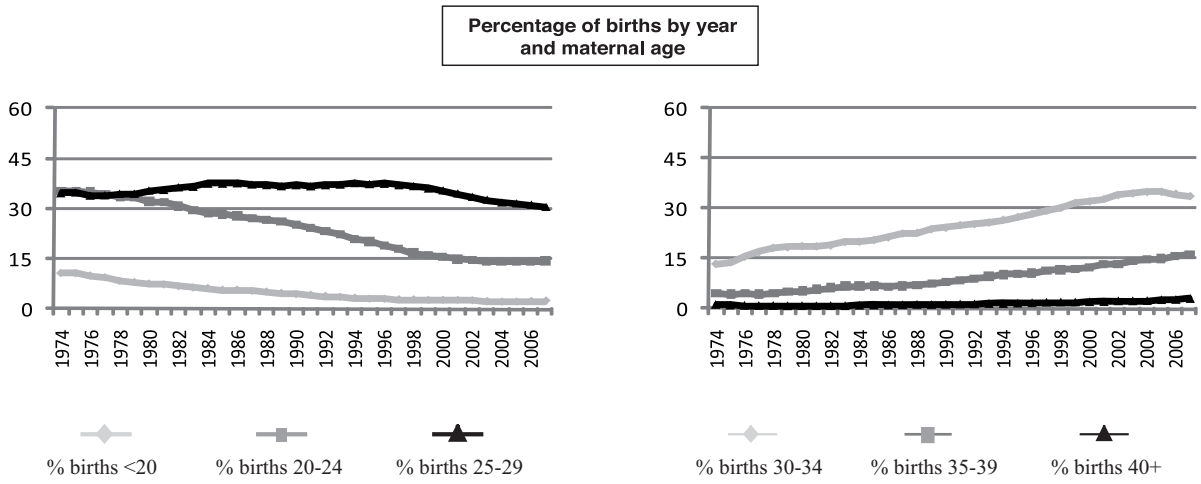
Norwegian Institute of Public Health
Kalfarveien 31
N-5018 Bergen, Norway
Phone: 47- 53 20 4002
Fax: 47 - 53 20 4001
E-mail: vollset@uib.no

Norway: MBRN





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	58	85.3	Cystic kidney	37	37.0
Spina bifida	42	45.7	Limb reduction defects	20	22.0
Encephalocele	7	53.8	Diaphragmatic hernia	10	25.0
Holoprosencephaly	16	76.2	Omphalocele	21	50.0
Hydrocephaly	38	34.2	Gastroschisis	9	15.8
Hypoplastic left heart syndrome	18	37.5	Trisomy 13	21	61.8
Cleft palate without cleft lip	2	1.4	Trisomy 18	41	58.6
Cleft lip with or without cleft palate	14	5.7	Down syndrome	88	27.3
Renal agenesis	12	46.2			

Total ToPs with births defects = 742 (Ratio ToPs/Births: 4.20 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Norway: MBRN, 2007

Live births (LB)	58,969
Stillbirths (SB)	404
Total births	59,373
Number of terminations of pregnancy (ToP) for birth defects	255

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	17	3.03
Spina bifida	13	0	22	5.89
Encephalocele	3	0	5	1.35
Microcephaly	2	0	0	0.34
Holoprosencephaly	1	0	8	1.52
Hydrocephaly	20	0	14	5.73
Anophthalmos	1	0	0	0.17
Microphthalmos	4	0	0	0.67
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	1	0	0	0.17
Microtia	0	0	0	0.00
Unspecified Anotia/Microtia	nr	nr	nr	nr
Transposition of great vessels	31	0	1	5.39
Tetralogy of Fallot	15	0	0	2.53
Hypoplastic left heart syndrome	14	0	12	4.38
Coarctation of aorta	19	0	4	3.87
Choanal atresia, bilateral	2	0	2	0.67
Cleft palate without cleft lip	33	2	2	6.23
Cleft lip with or without cleft palate	66	2	10	13.14
Oesophageal atresia/stenosis with or without fistula	19	0	4	3.87
Small intestine atresia/stenosis	5	0	0	0.84
Anorectal atresia/stenosis	15	0	10	4.21
Undescended testis (36 weeks of gestation or later)	160	0	0	26.95
Hypospadias	83	0	1	14.15
Epispadias	0	0	0	0.00
Indeterminate sex	3	0	0	0.51
Renal agenesis	4	1	12	2.86
Cystic kidney	16	0	13	4.88
Bladder exstrophy	2	0	2	0.67
Polydactyly, preaxial	39	0	4	7.24
Total Limb reduction defects (include unspecified)	18	0	12	5.05
Transverse	9	0	2	1.85
Preaxial	1	0	4	0.84
Postaxial	1	0	0	0.17
Intercalary	1	0	1	0.34
Mixed	8	0	6	2.36
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	14	0	5	3.20
Omphalocele	4	3	11	3.03
Gastroschisis	24	1	1	4.38
Unspecified Omphalocele/Gastroschisis	1	1	1	0.51
Prune belly sequence	3	0	8	1.85
Trisomy 13	5	1	10	2.69
Trisomy 18	11	1	18	5.05
Down syndrome, all ages (include age unknown)	67	7	47	20.38
<20	0	0	0	0.00
20-24	3	1	0	4.70
25-29	8	1	4	7.22
30-34	20	0	7	13.53
35-39	24	2	16	43.22
40-44	11	3	19	198.20
45+	1	0	1	289.86
unknown	0	0	0	---

nr = not reported

Norway: MBRN, Previous years rates 1974 - 2007

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

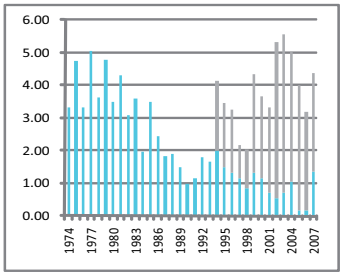
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**222,984**	**258,731**	**259,628**	**301,537**	**302,352**	**292,337**	**292,075**
Anencephaly	4.08	3.87	2.66	1.46	2.94	3.73	4.42
Spina bifida	5.43	5.14	4.93	4.38	4.37	4.72	5.03
Encephalocele	0.49	0.62	0.69	0.43	0.63	0.89	0.99
Microcephaly	0.76	0.46	0.81	0.53	0.53	0.65	0.75
Holoprosencephaly	0.04	0.08	0.46	0.46	0.89	0.75	1.20
Hydrocephaly	3.72	4.14	3.70	3.25	3.27	4.28	6.03
Anophthalmos	0.00	0.12	0.12	0.20	0.03	0.07	0.14
Microphthalmos	0.13	0.23	0.23	0.43	0.10	0.24	0.55
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.18	0.08	0.31	0.10	0.23	0.24	0.14
Microtia	nr	nr	1.49*	1.03	0.23	0.51	0.72
Unspecified Anotia / Microtia	nr	nr	nr	nr	nr	nr	nr
Transposition of great vessels	0.36	0.73	0.54	2.42	1.79	3.11	3.87
Tetralogy of Fallot	0.13	0.19	0.31	0.96	1.09	2.60	2.47
Hypoplastic left heart syndrome	nr	nr	0.36*	1.29	1.98	2.70	2.94
Coarctation of aorta	nr	0.43*	0.46	1.06	0.73	2.09	2.74
Choanal atresia, bilateral	0.22	0.27	0.65	0.40	0.60	0.51	0.58
Cleft palate without cleft lip	4.44	5.02	5.47	5.37	5.42	6.12	7.43
Cleft lip with or without cleft palate	14.22	14.30	13.90	13.27	13.92	12.62	13.49
Oesophageal atresia / stenosis with or without fistula	2.33	1.58	1.81	2.65	1.62	3.01	2.36
Small intestine atresia / stenosis	0.85	0.93	1.08	1.53	1.49	1.20	0.92
Anorectal atresia / stenosis	1.70	1.62	2.23	2.62	1.75	2.67	3.05
Undescended testis (36 weeks of gestation or later)	17.85	16.12	14.75	17.61	15.91	22.92	27.73
Hypospadias	11.75	14.03	14.91	16.65	14.39	16.08	15.61
Epispadias	0.27	0.19	0.54	0.30	0.26	0.34	0.10
Indeterminate sex	1.75	3.87	3.62	4.68	8.04	1.98	0.41
Renal agenesis	0.09	0.35	0.96	1.69	1.42	1.44	1.13
Cystic kidney	0.45	0.70	1.31	2.22	2.41	4.52	5.27
Bladder exstrophy	0.27	0.35	0.35	0.30	0.36	0.27	0.27
Polydactyly, preaxial	nr	nr	nr	nr	nr	8.21*	9.52
'Total Limb reduction defects (include unspecified)	7.85	8.08	7.66	6.27	6.88	4.69	4.79
Transverse	nr	nr	nr	3.24*	3.57	2.26	2.33
Preaxial	nr	nr	nr	0.86*	0.30	0.55	0.48
Postaxial	nr	nr	nr	0.69*	0.46	0.17	0.10
Intercalary	nr	nr	nr	0.12*	0.66	0.17	0.14
Mixed	nr	nr	nr	0.45*	0.83	1.44	1.99
Unspecified	nr	nr	nr	nr	nr	nr	nr
Diaphragmatic hernia	1.52	2.55	2.54	2.49	2.55	2.63	2.43
Omphalocele	2.69	1.74	2.23	1.89	2.18	2.19	2.29
Gastroschisis	1.26	1.39	1.62	1.86	2.84	2.70	2.81
Unspecified Omphalocele / Gastroschisis	nr	nr	nr	nr	nr	0.72*	0.51
Prune belly sequence	nr	nr	nr	nr	nr	1.19*	1.57
Trisomy 13	nr	nr	nr	nr	nr	1.32*	1.57
Trisomy 18	nr	nr	nr	nr	nr	3.20*	3.77
Down syndrome, all ages (include age unknown)	9.55	10.28	10.86	10.18	11.21	14.91	18.93
<20	1.74	4.05	3.95	2.99	3.23	5.28	7.80
20-24	6.03	6.83	7.65	6.08	3.64	3.73	6.04
25-29	6.93	8.66	6.09	5.93	6.90	7.47	8.50
30-34	11.40	10.58	14.90	12.18	11.30	11.62	14.13
35-39	36.33	35.72	35.67	28.43	27.90	41.42	44.95
40-44	149.95	97.37	59.29	78.51	105.42	128.25	137.10
45+	222.22	88.50	288.46	327.87	251.57	277.78	166.11
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

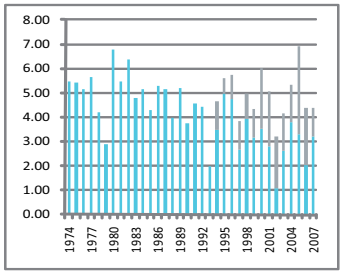
Norway: MBRN

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

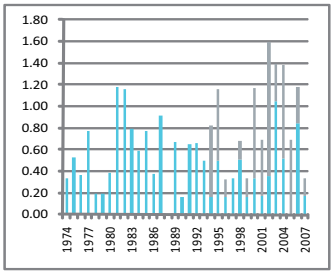
Anencephaly



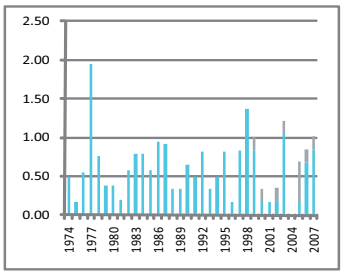
Spina Bifida



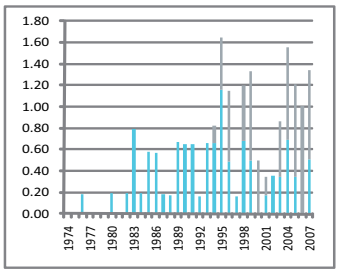
Encephalocele



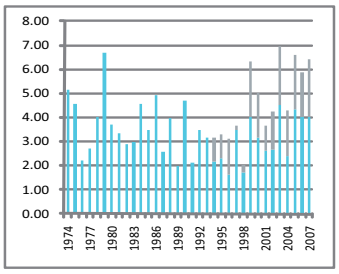
Microcephaly



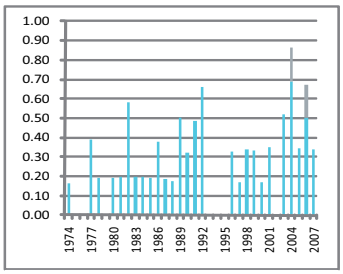
Holoprosencephaly



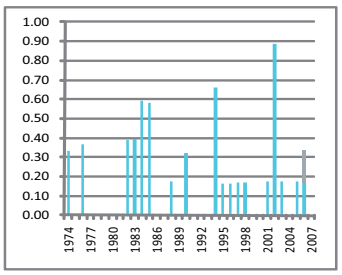
Hydrocephaly



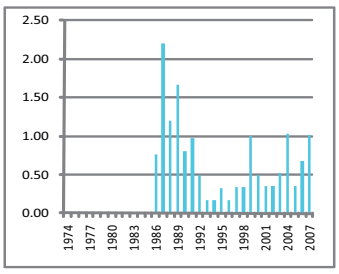
Microphthalmos



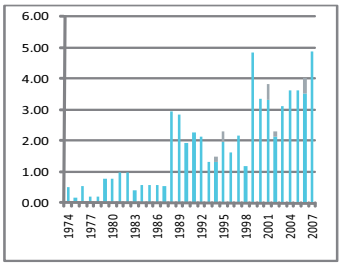
Anotia



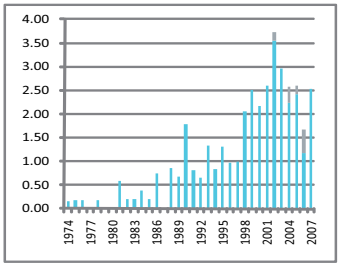
Microtia



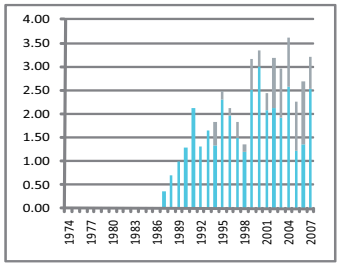
Transposition of great vessels



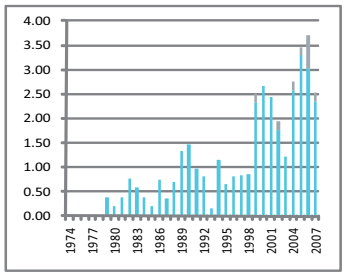
Tetralogy of Fallot



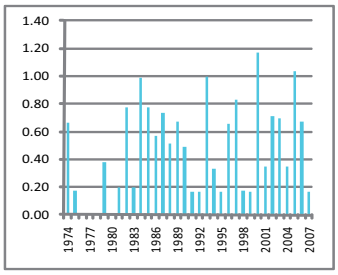
Hypoplastic left heart syndrome



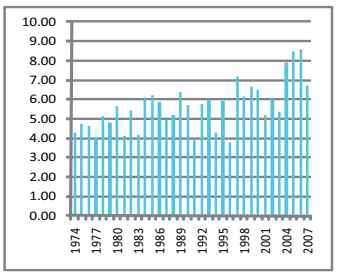
Coarctation of aorta



Choanal atresia, bilateral



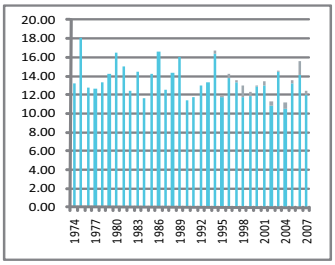
Cleft palate without cleft lip



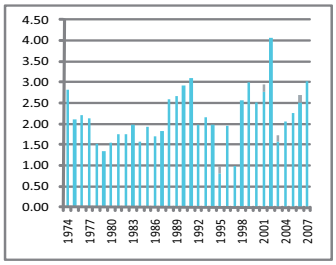
Note: L+S rates, ToP rates

Norway: MBRN

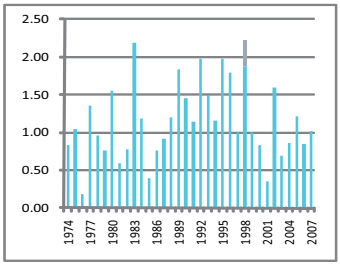
Cleft lip with or without cleft palate



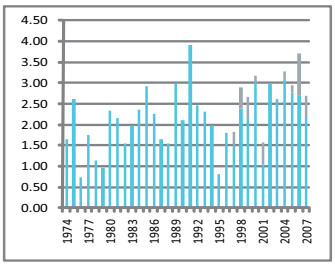
Oesophageal atresia/stenosis with or without fistula



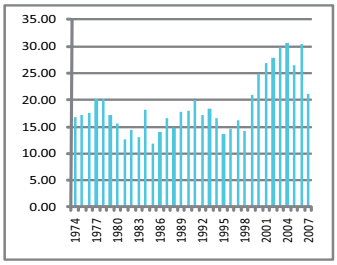
Small intestine atresia/stenosis



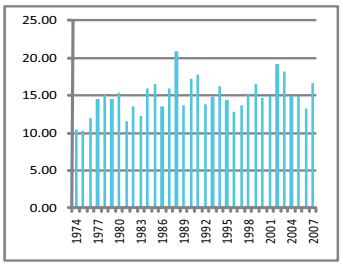
Anorectal atresia/stenosis



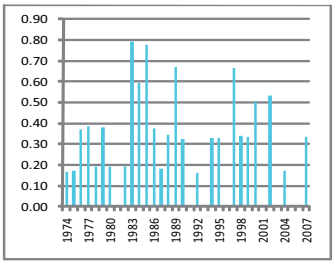
Undescended testis



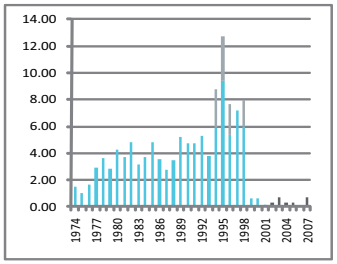
Hypospadias



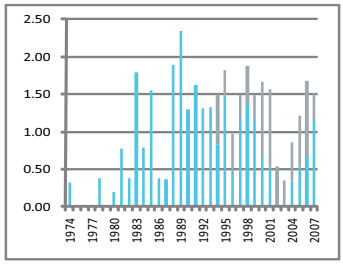
Epispadias



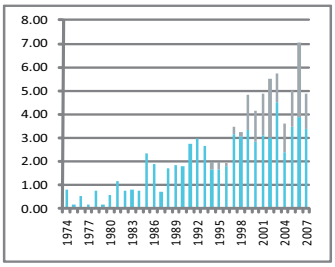
Indeterminate sex



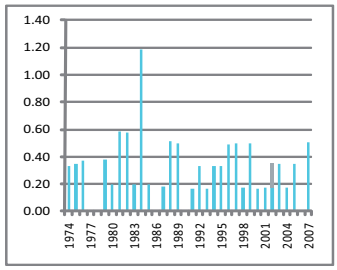
Renal agenesis



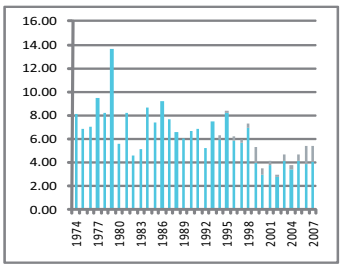
Cystic kidney



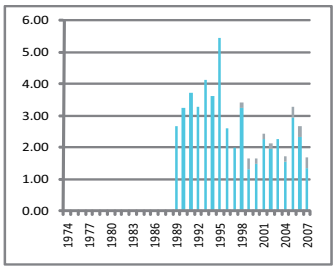
Bladder exstrophy



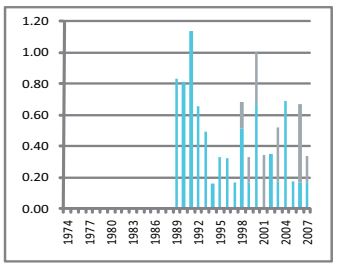
Limb reduction defects



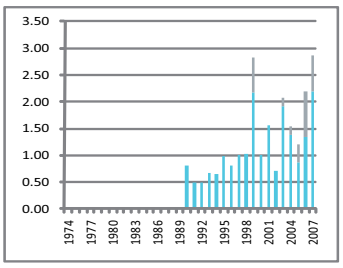
Limb reduction defects - transverse



Limb reduction defects - preaxial



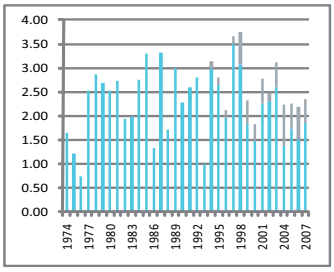
Limb reduction defects - mixed



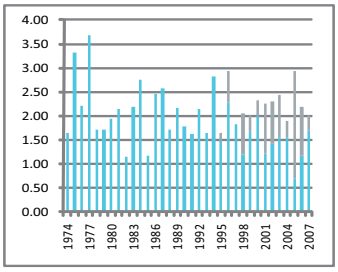
Note: L+S rates, ToP rates

Norway: MBRN

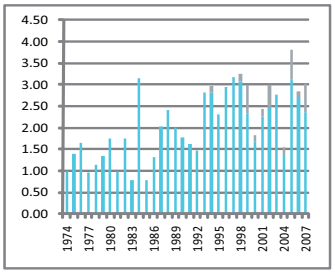
Diaphragmatic hernia



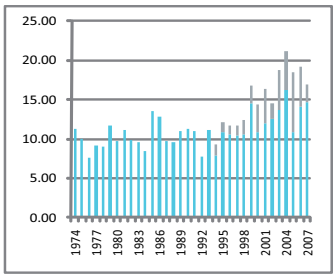
Omphalocele



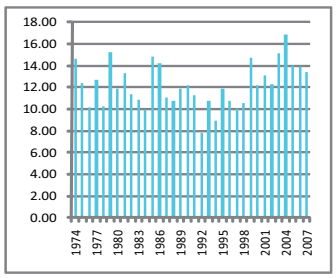
Gastroschisis



Down Syndrome



Down Syndrome standardized total rate



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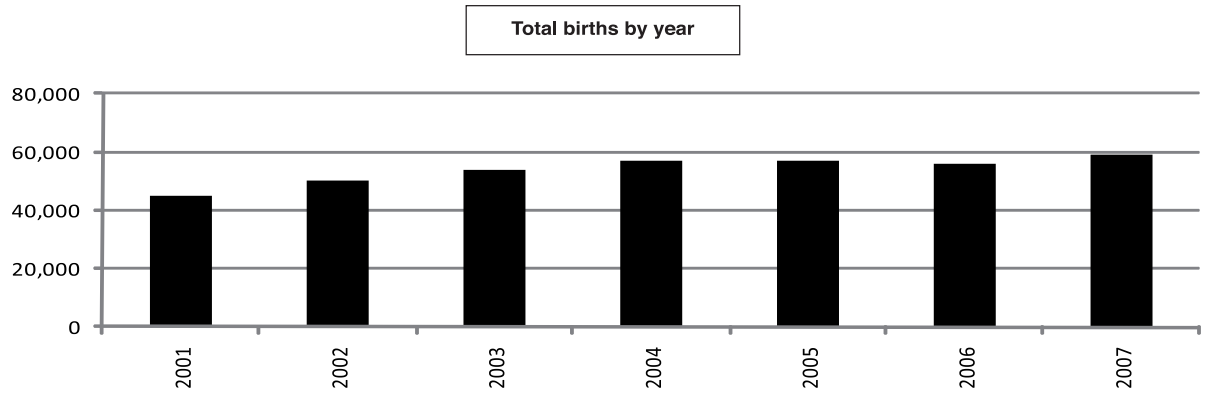
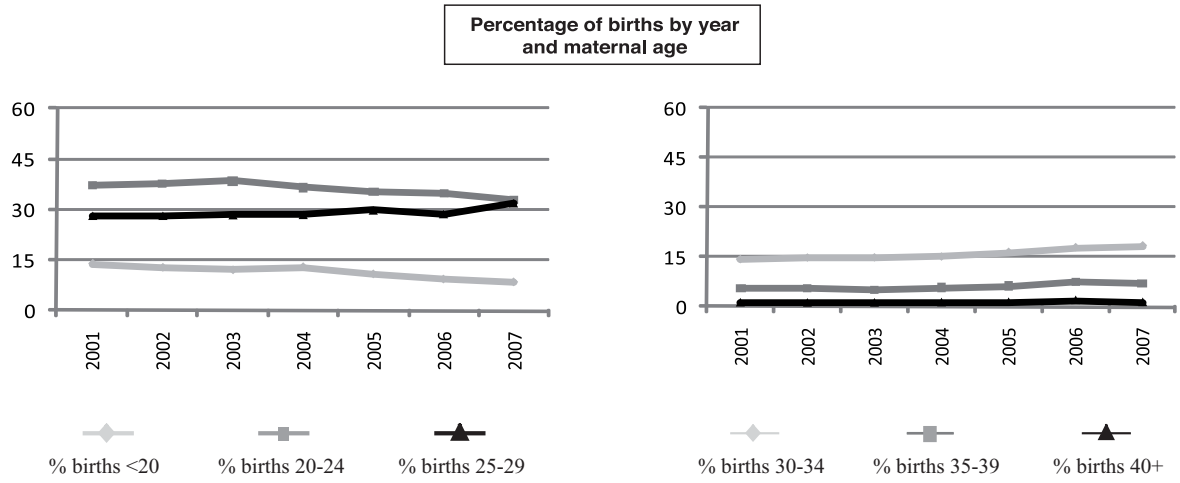
22a, Pokrovka St.
101000 Moscow Russia
Phone: 007-0959356228
Fax: 007-0959215398
E-mail: mrrcm@mail.ru

Russia: MRRCM





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	44	84.6	Cystic kidney	13	21.3
Spina bifida	21	28.0	Limb reduction defects	5	12.5
Encephalocele	10	50.0	Diaphragmatic hernia	3	8.1
Holoprosencephaly	5	71.4	Omphalocele	13	31.0
Hydrocephaly	35	36.5	Gastroschisis	24	37.5
Hypoplastic left heart syndrome	10	38.5	Trisomy 13	2	100.0
Cleft palate without cleft lip	0	0.0	Trisomy 18	6	60.0
Cleft lip with or without cleft palate	11	9.7	Down syndrome	18	7.6
Renal agenesis	14	37.8			

Total ToPs with births defects = 529 (Ratio ToPs/Births: 3.07 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Russia: MRRCM, 2007

Live births (LB)	58,882
Stillbirths (SB)	348
Total births	59,230
Number of terminations of pregnancy (ToP) for birth defects	211

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	6	1.01
Spina bifida	24	0	12	6.08
Encephalocele	3	0	3	1.01
Microcephaly	1	0	6	1.18
Holoprosencephaly	0	0	2	0.34
Hydrocephaly	11	2	13	4.39
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	7	0	0	1.18
Microtia	4	0	0	0.68
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	7	0	0	1.18
Tetralogy of Fallot	5	0	1	1.01
Hypoplastic left heart syndrome	8	0	4	2.03
Coarctation of aorta	1	1	0	0.34
Choanal atresia, bilateral	2	0	0	0.34
Cleft palate without cleft lip	27	1	0	4.73
Cleft lip with or without cleft palate	36	1	4	6.92
Oesophageal atresia/stenosis with or without fistula	9	0	1	1.69
Small intestine atresia/stenosis	10	0	0	1.69
Anorectal atresia/stenosis	17	0	1	3.04
Undescended testis (36 weeks of gestation or later)	90	0	0	15.20
Hypospadias	90	0	0	15.20
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	0	0.17
Renal agenesis	3	0	7	1.69
Cystic kidney	18	1	7	4.39
Bladder exstrophy	1	0	0	0.17
Polydactyly, preaxial	12	0	0	2.03
Total Limb reduction defects (include unspecified)	14	0	2	2.70
Transverse	5	0	2	1.18
Preaxial	0	0	0	0.00
Postaxial	1	0	0	0.17
Intercalary	0	0	0	0.00
Mixed	4	0	0	0.68
Unspecified	4	0	0	0.68
Diaphragmatic hernia	11	1	3	2.53
Omphalocele	8	1	7	2.70
Gastroschisis	9	2	11	3.71
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	1	0	2	0.51
Down syndrome, all ages (include age unknown)	64	1	7	12.16
<20	2	1	0	5.90
20-24	13	0	1	7.20
25-29	12	0	1	6.86
30-34	11	0	3	12.89
35-39	14	0	1	36.22
40-44	10	0	1	150.07
45+	1	0	0	370.37
unknown	1	0	0	---

nr = not reported

Russia: MRRCM, Previous years rates 2001 - 2007

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

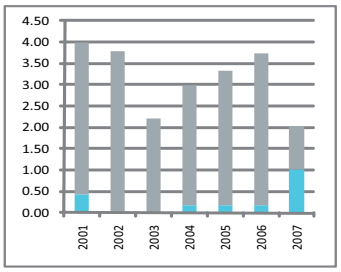
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002*	2003-2007
Total births						**95,394**	**283,822**
Anencephaly						3.88	2.85
Spina bifida						5.56	4.19
Encephalocele						0.63	0.81
Microcephaly						0.94	0.95
Holoprosencephaly						0.21	0.28
Hydrocephaly						6.29	5.18
Anophthalmos						0.10	0.11
Microphthalmos						0.00	0.14
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.00	0.35
Microtia						0.10	0.53
Unspecified Anotia / Microtia						0.94	0.18
Transposition of great vessels						2.31	1.94
Tetralogy of Fallot						1.57	1.16
Hypoplastic left heart syndrome						0.52	1.20
Coarctation of aorta						0.00	0.70
Choanal atresia, bilateral						0.52	0.39
Cleft palate without cleft lip						4.51	4.69
Cleft lip with or without cleft palate						7.86	6.76
Oesophageal atresia / stenosis with or without fistula						2.41	1.76
Small intestine atresia / stenosis						1.15	1.09
Anorectal atresia / stenosis						2.10	2.47
Undescended testis (36 weeks of gestation or later)						24.11	16.07
Hypospadias						18.76	13.53
Epispadias						0.21	0.07
Indeterminate sex						0.63	0.46
Renal agenesis						1.99	1.73
Cystic kidney						3.25	3.17
Bladder exstrophy						0.00	0.21
Polydactyly, preaxial						11.43	4.37
‘Total Limb reduction defects (include unspecified)						4.82	2.43
Transverse						1.57	1.41
Preaxial						0.42	0.25
Postaxial						0.21	0.11
Intercalary						0.21	0.04
Mixed						0.21	0.70*
Unspecified						2.20	0.48*
Diaphragmatic hernia						0.94	2.11
Omphalocele						5.66	2.15
Gastroschisis						3.04	3.31
Unspecified Omphalocele / Gastroschisis						0.10	0.92
Prune belly sequence						0.10	0.00
Trisomy 13						0.21	0.14
Trisomy 18						0.31	0.42
Down syndrome, all ages (include age unknown)						11.85	12.97
<20						7.08	5.57
20-24						7.56	6.94
25-29						8.92	7.52
30-34						10.87	17.31
35-39						44.28	42.28
40-44						123.57	143.37
45+						263.16	317.46
unknown						---	---

nr = not reported
* data include less than 5 years

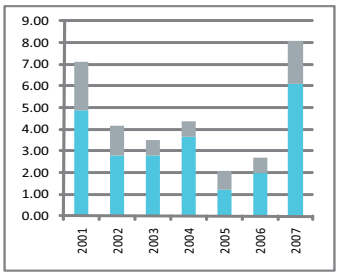
Russia: MRRCM

'Time trends 2001-2007 (Birth prevalence rates per 10,000)

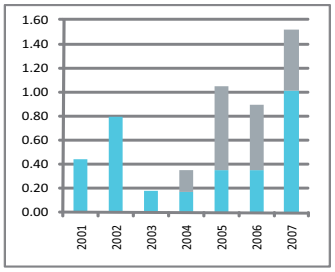
Anencephaly



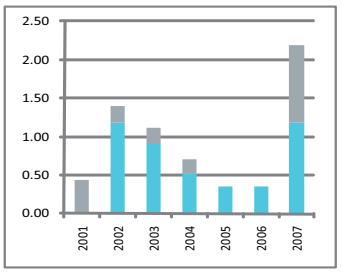
Spina Bifida



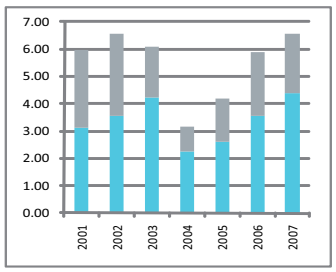
Encephalocele



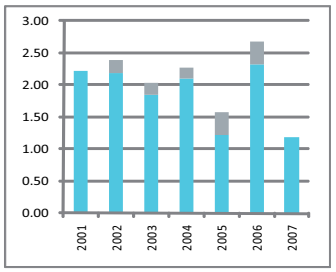
Microcephaly



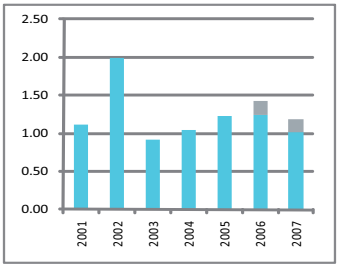
Hydrocephaly



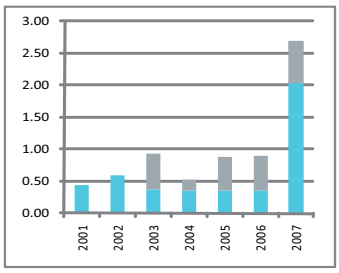
Transposition of great vessels



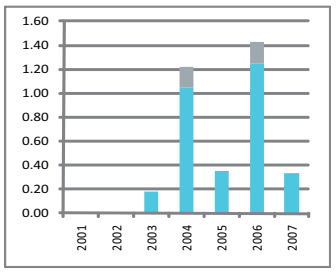
Tetralogy of Fallot



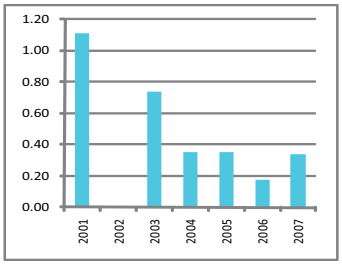
Hypoplastic left heart syndrome



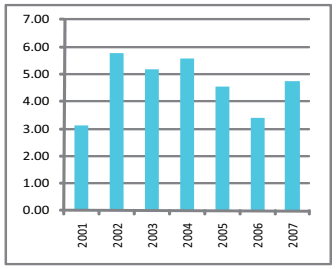
Coarctation of aorta



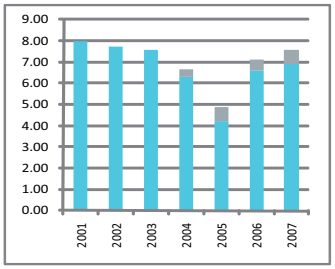
Choanal atresia, bilateral



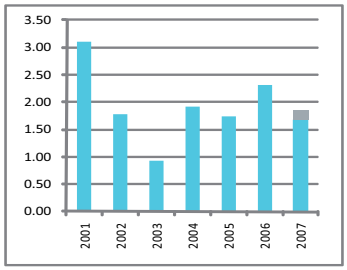
Cleft palate without cleft lip



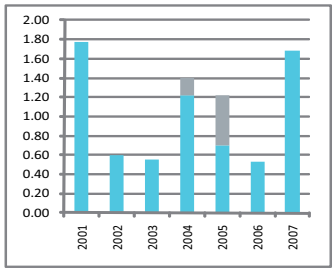
Cleft lip with or without cleft palate



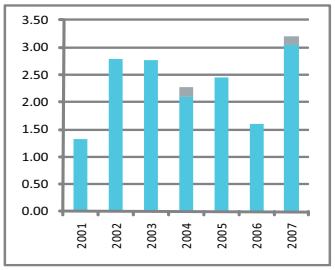
Oesophageal atresia/stenosis with or without fistula



Small intestine atresia/stenosis



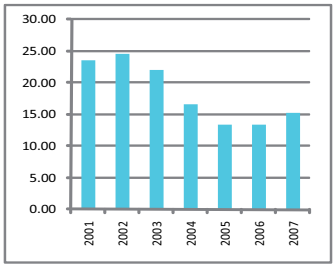
Anorectal atresia/stenosis



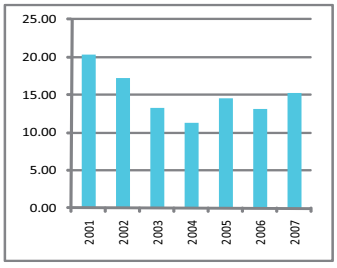
Note: L+S rates, ToP rates

Russia: MRRCM

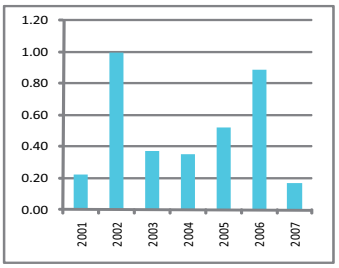
Undescended testis



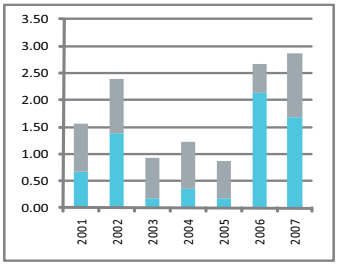
Hypospadias



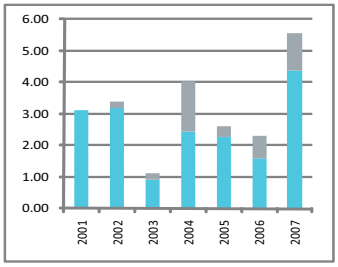
Indeterminate sex



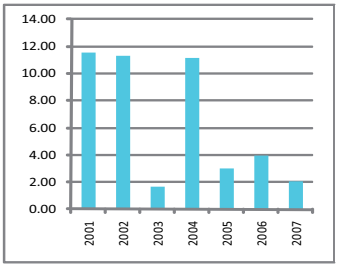
Renal agenesis



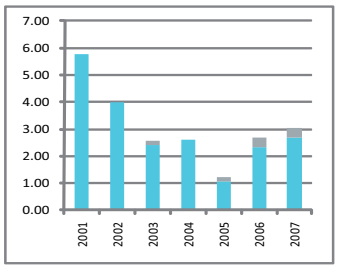
Cystic kidney



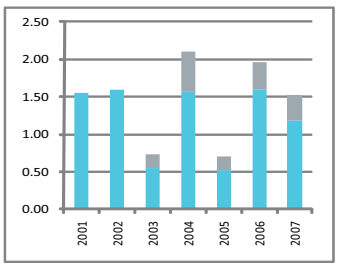
Polydactyly, preaxial



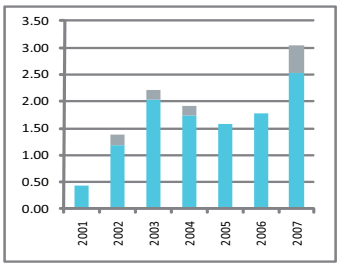
Limb reduction defects



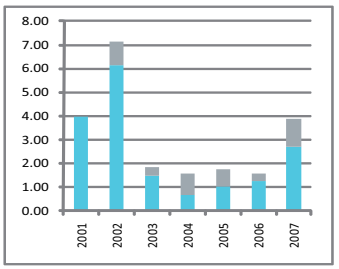
Limb reduction defects - transverse



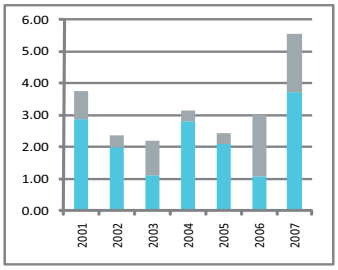
Diaphragmatic hernia



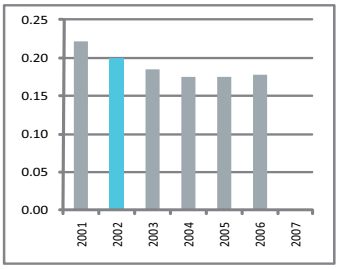
Omphalocele



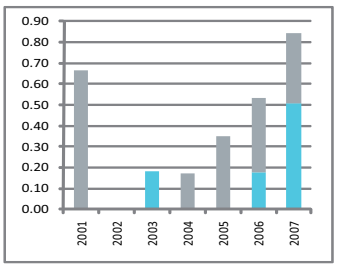
Gastroschisis



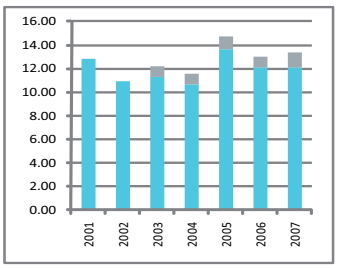
Trisomy 13



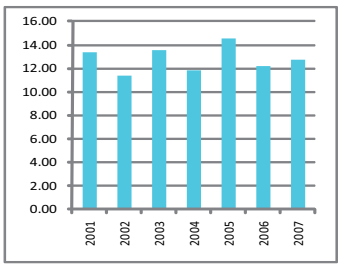
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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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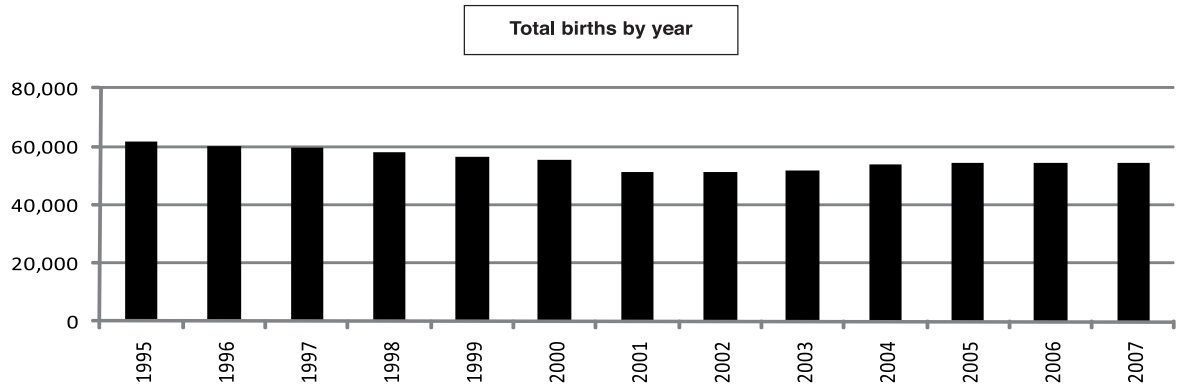
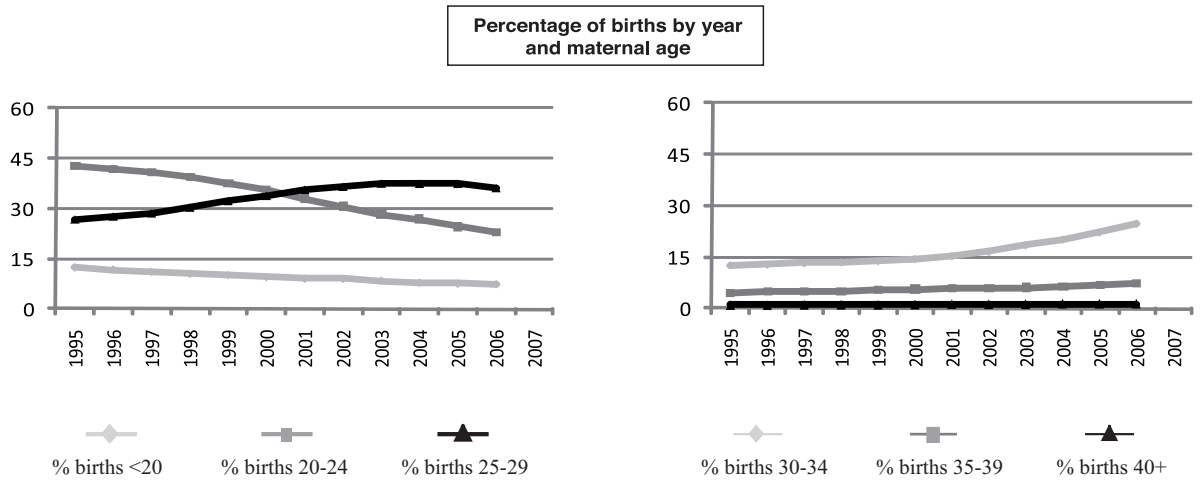
Slovak Republic





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	14	82.4	Cystic kidney	1	4.8
Spina bifida	5	14.7	Limb reduction defects	0	0.0
Encephalocele	7	50.0	Diaphragmatic hernia	0	0.0
Holoprosencephaly	1	16.7	Omphalocele	0	0.0
Hydrocephaly	12	19.4	Gastroschisis	1	6.7
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	1	16.7
Cleft palate without cleft lip	1	1.2	Trisomy 18	0	0.0
Cleft lip with or without cleft palate	0	0.0	Down syndrome	16	11.8
Renal agenesis	0	0.0			

Total ToPs with births defects = 98 (Ratio ToPs/Births: 0.60 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Slovak Republic: 2007

Live births (LB)	54,424
Stillbirths (SB)	207
Total births	54,631
Number of terminations of pregnancy (ToP) for birth defects	28

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	6	1.28
Spina bifida	7	0	2	1.65
Encephalocele	2	0	3	0.92
Microcephaly	6	0	0	1.10
Holoprosencephaly	1	0	0	0.18
Hydrocephaly	12	0	3	2.75
Anophthalmos	0	0	0	0.00
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	nr	nr	nr	nr
Anotia	1	0	0	0.18
Microtia	1	0	0	0.18
Unspecified Anotia/Microtia	4	0	0	0.73
Transposition of great vessels	5	0	0	0.92
Tetralogy of Fallot	11	0	0	2.01
Hypoplastic left heart syndrome	7	0	0	1.28
Coarctation of aorta	6	0	0	1.10
Choanal atresia, bilateral	2	0	0	0.37
Cleft palate without cleft lip	21	0	0	3.84
Cleft lip with or without cleft palate	48	1	0	8.97
Oesophageal atresia/stenosis with or without fistula	9	0	0	1.65
Small intestine atresia/stenosis	10	1	0	2.01
Anorectal atresia/stenosis	17	0	0	3.11
Undescended testis (36 weeks of gestation or later)	55	0	0	10.07
Hypospadias	84	0	0	15.38
Epispadias	1	0	0	0.18
Indeterminate sex	1	0	0	0.18
Renal agenesis	30	0	0	5.49
Cystic kidney	4	0	0	0.73
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	13	0	0	2.38
Total Limb reduction defects (include unspecified)	14	1	0	2.75
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	0	0	0	0.00
Diaphragmatic hernia	8	0	0	1.46
Omphalocele	3	0	0	0.55
Gastroschisis	4	0	0	0.73
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	1	0	0	0.18
Trisomy 13	0	1	1	0.37
Trisomy 18	0	0	0	0.00
Down syndrome, all ages (include age unknown)	31	0	6	6.77
<20	1	0	1	4.96
20-24	3	0	1	3.42
25-29	7	0	0	3.66
30-34	10	0	3	8.92
35-39	5	0	1	13.58
40-44	4	0	0	51.22
45+	1	0	0	270.27
unknown	0	0	0	---

nr = not reported

Slovak Republic: Previous years rates 1995 - 2007

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

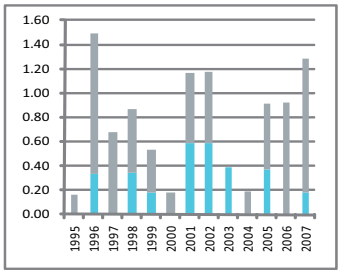
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997*	1998-2002	2003-2007
Total births					**181,387**	**272,089**	**269,266**
Anencephaly					0.77	0.77	0.74
Spina bifida					3.36	3.68	2.38
Encephalocele					1.32	1.14	1.04
Microcephaly					1.60	1.07	1.00
Holoprosencephaly					0.17	0.22	0.37
Hydrocephaly					5.24	5.15	4.05
Anophthalmos					0.00	0.11	0.04
Microphthalmos					0.22	0.11	0.37
Unspecified Anophthalmos / Microphthalmos					0.00	0.00	0.00
Anotia					0.06	0.18	0.07
Microtia					0.33	0.37	0.19
Unspecified Anotia / Microtia					0.17	0.33	0.67
Transposition of great vessels					0.94	0.96	1.26
Tetralogy of Fallot					0.88	1.40	1.52
Hypoplastic left heart syndrome					0.94	2.02	1.97
Coarctation of aorta					0.39	0.48	1.00
Choanal atresia, bilateral					0.28	0.15	0.19
Cleft palate without cleft lip					5.35	5.77	4.98
Cleft lip with or without cleft palate					9.92	10.55	9.25
Oesophageal atresia / stenosis with or without fistula					0.66	1.65	1.52
Small intestine atresia / stenosis					1.54	1.58	2.27
Anorectal atresia / stenosis					1.05	2.79	2.82
Undescended testis (36 weeks of gestation or later)					5.73	7.53	8.95
Hypospadias					23.43	22.86	21.13
Epispadias					0.06	0.26	0.19
Indeterminate sex					0.39	0.55	0.19
Renal agenesis					1.98	4.45	6.02
Cystic kidney					0.55	1.36	1.56
Bladder exstrophy					0.00	0.26	0.11
Polydactyly, preaxial					1.60	2.68	2.93
‘Total Limb reduction defects (include unspecified)					3.97	3.16	3.90
Transverse					nr	nr	nr
Preaxial					nr	nr	nr
Postaxial					nr	nr	nr
Intercalary					nr	nr	nr
Mixed					nr	nr	nr
Unspecified					0.06	0.00	0.05
Diaphragmatic hernia					0.99	1.62	1.56
Omphalocele					0.50	0.70	0.59
Gastroschisis					0.55	1.18	1.04
Unspecified Omphalocele / Gastroschisis					0.00	0.00	0.00
Prune belly sequence					0.00	0.04	0.26
Trisomy 13					0.11	0.48	0.30
Trisomy 18					0.17	0.37	0.52
Down syndrome, all ages (include age unknown)					9.15	9.63	9.51
<20					6.60	6.47	2.40
20-24					6.59	4.78	4.35
25-29					6.57	7.11	5.68
30-34					14.96	9.49	11.20
35-39					27.05	41.94	32.68
40-44					51.49	100.64	94.37
45+					147.06	250.00	259.74
unknown					---	---	---

nr = not reported
* data include less than 5 years

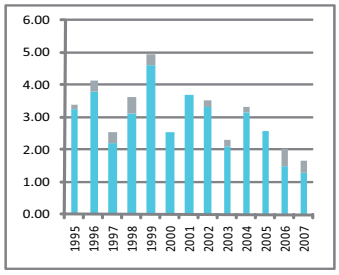
Slovak Republic

'Time trends 1995-2007 (Birth prevalence rates per 10,000)

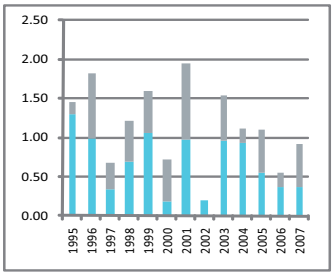
Anencephaly



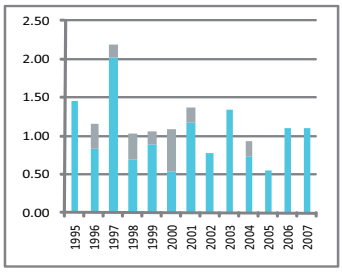
Spina Bifida



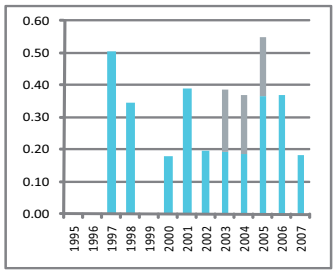
Encephalocele



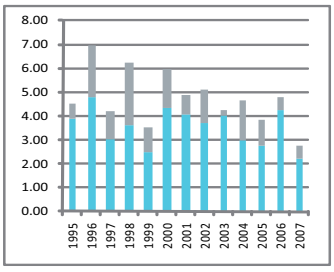
Microcephaly



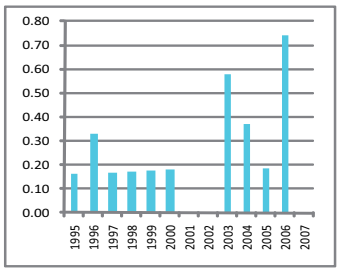
Holoprosencephaly



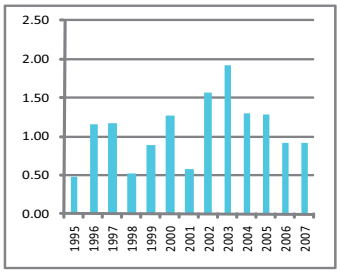
Hydrocephaly



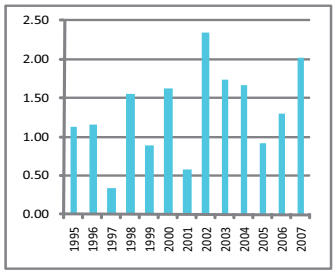
Microphthalmos



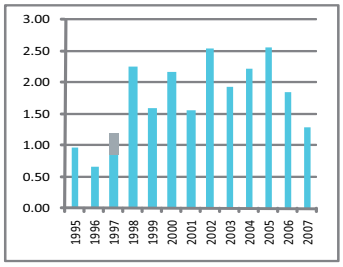
Transposition of great vessels



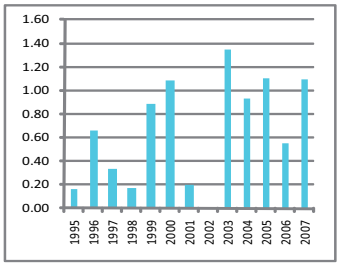
Tetralogy of Fallot



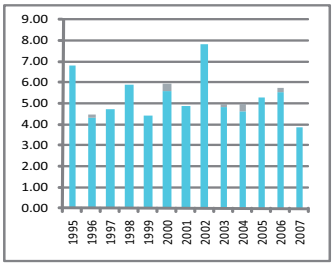
Hypoplastic left heart syndrome



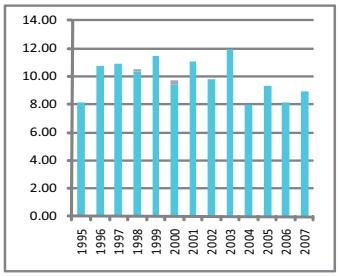
Coarctation of aorta



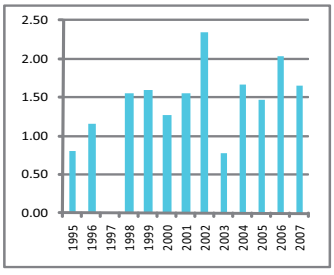
Cleft palate without cleft lip



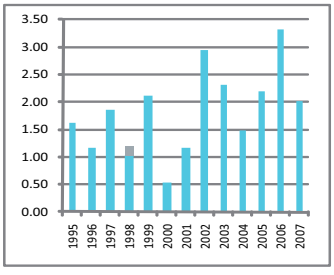
Cleft lip with or without cleft palate



Oesophageal atresia/stenosis with or without fistula



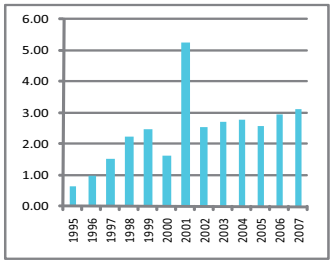
Small intestine atresia/stenosis



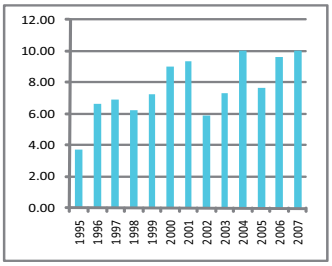
Note: L+S rates, ToP rates

Slovak Republic

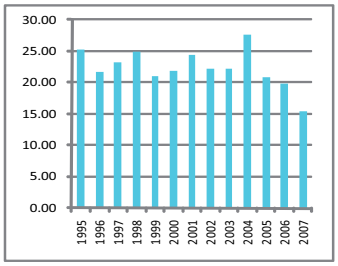
Anorectal atresia/stenosis



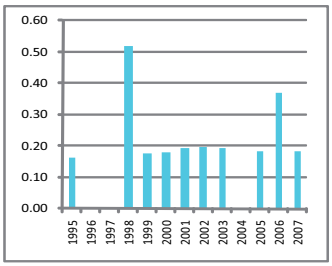
Undescended testis



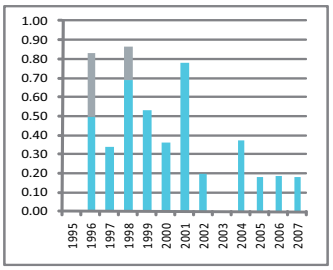
Hypospadias



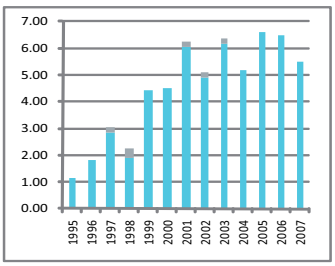
Epispadias



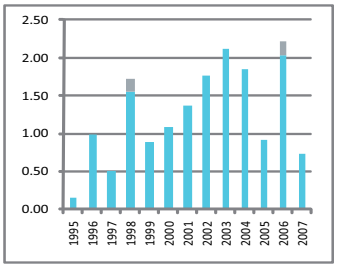
Indeterminate sex



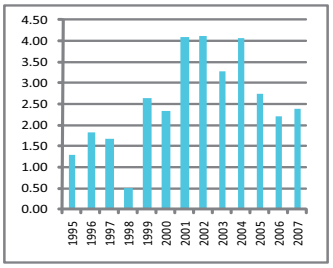
Renal agenesis



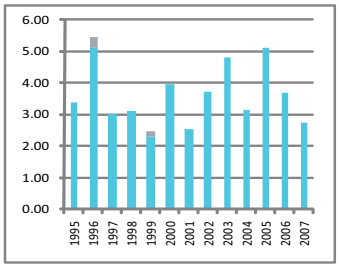
Cystic kidney



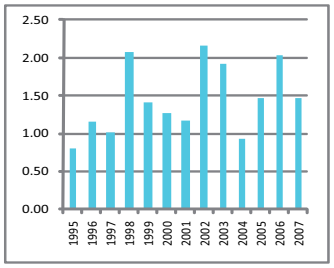
Polydactyly, preaxial



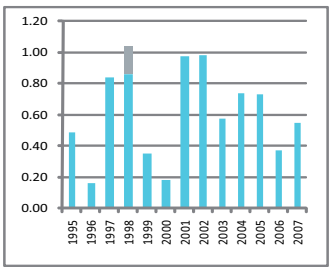
Limb reduction defects



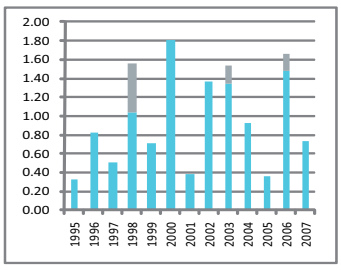
Diaphragmatic hernia



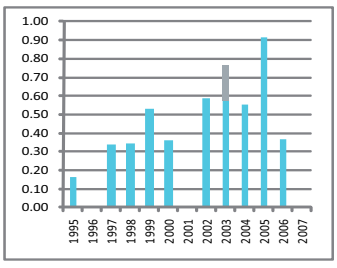
Omphalocele



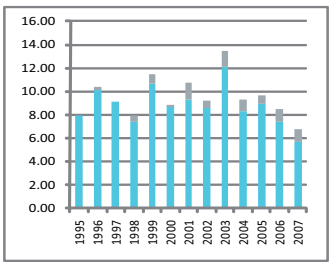
Gastroschisis



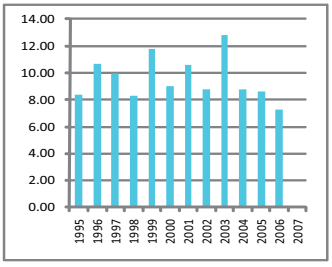
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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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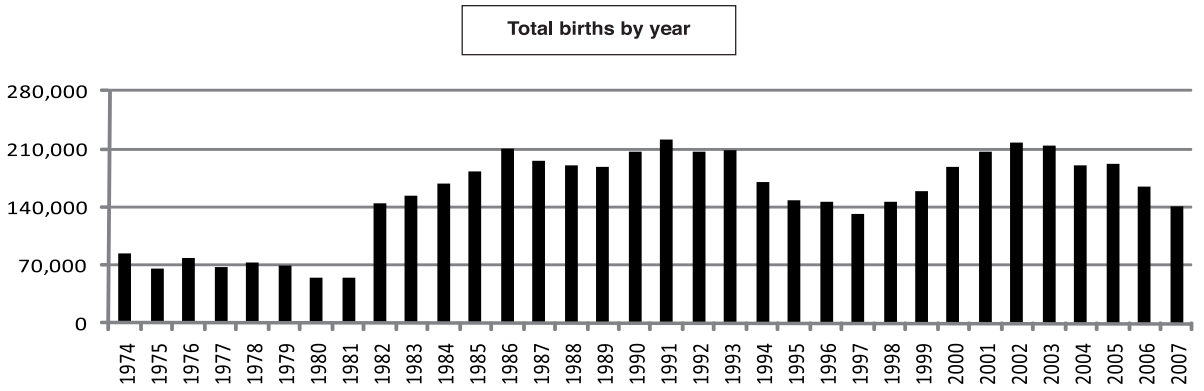
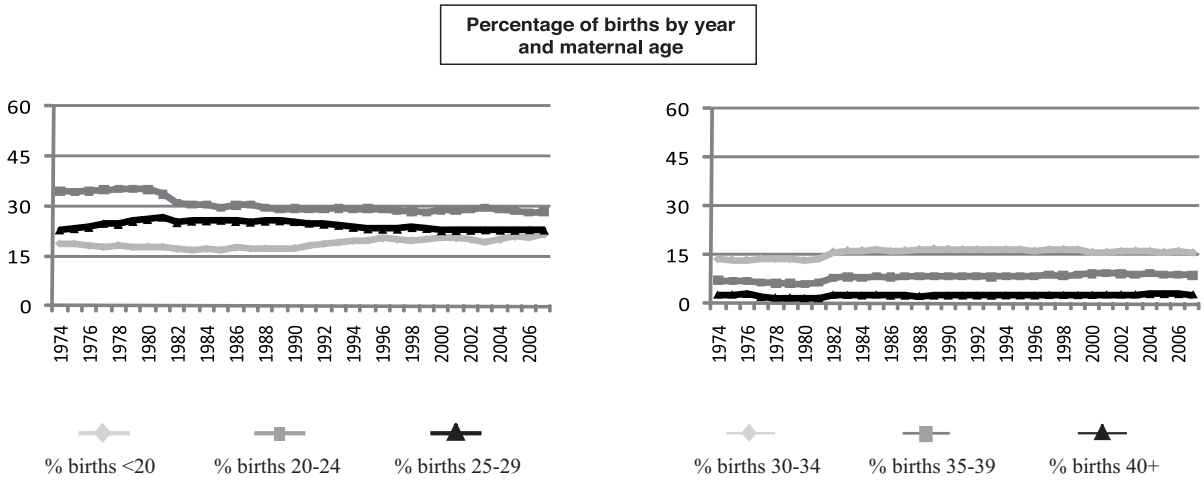
South America: ECLAMC





South America: ECLAMC, 2007

Live births (LB)	138,733
Stillbirths (SB)	1,757
Total births	140,490
Number of terminations of pregnancy (ToP) for birth defects	Not permitted

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	37	39		5.41
Spina bifida	121	18		9.89
Encephalocele	32	13		3.20
Microcephaly	49	6		3.91
Holoprosencephaly	1	2		0.21
Hydrocephaly	163	15		12.67
Anophthalmos	18	7		1.78
Microphthalmos	23	3		1.85
Unspecified Anophthalmos/Microphthalmos	0	0		0.00
Anotia	1	2		0.21
Microtia	77	4		5.77
Unspecified Anotia/Microtia	0	0		0.00
Transposition of great vessels	14	0		1.00
Tetralogy of Fallot	24	1		1.78
Hypoplastic left heart syndrome	14	4		1.28
Coarctation of aorta	8	3		0.78
Choanal atresia, bilateral	3	0		0.21
Cleft palate without cleft lip	52	4		3.99
Cleft lip with or without cleft palate	183	20		14.45
Oesophageal atresia/stenosis with or without fistula	57	5		4.41
Small intestine atresia/stenosis	29	3		2.28
Anorectal atresia/stenosis	62	7		4.91
Undescended testis (36 weeks of gestation or later)	158	1		11.32
Hypospadias	148	0		10.53
Epispadias	5	0		0.36
Indeterminate sex	42	12		3.84
Renal agenesis	28	6		2.42
Cystic kidney	55	2		4.06
Bladder exstrophy	3	0		0.21
Polydactyly, preaxial	46	1		3.35
Total Limb reduction defects (include unspecified)	110	20		9.25
Transverse	36	3		2.78
Preaxial	14	5		1.35
Postaxial	5	1		0.43
Intercalary	5	4		0.64
Mixed	23	3		1.85
Unspecified	27	4		2.21
Diaphragmatic hernia	51	6		4.06
Omphalocele	55	9		4.56
Gastroschisis	124	8		9.40
Unspecified Omphalocele/Gastroschisis	0	0		0.00
Prune belly sequence	9	3		0.85
Trisomy 13	6	3		0.64
Trisomy 18	12	2		1.00
Down syndrome, all ages (include age unknown)	277	9		20.36
<20	28	0		9.36
20-24	33	0		8.41
25-29	50	3		16.65
30-34	38	2		18.45
35-39	61	2		52.04
40-44	58	2		164.52
45+	9	0		338.35
unknown	0	0		0.00

South America: ECLAMC, Previous years rates 1974 - 2007

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

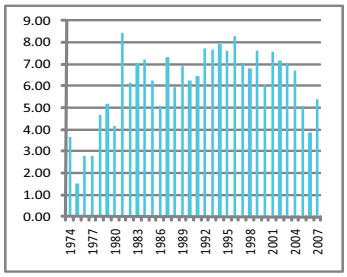
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**295,599**	**397,995**	**912,538**	**1,013,241**	**803,661**	**919,218**	**903,630**
Anencephaly	2.77	5.75	6.52	6.67	7.74	7.05	5.72
Spina bifida	5.82	6.18	6.77	7.20	9.17	10.29	9.50
Encephalocele	1.35	1.93	1.57	2.09	2.18	2.85	2.83
Microcephaly	2.33	2.51	2.81	2.44	3.12	3.61	3.98
Holoprosencephaly	0.20	0.63	0.42	0.35	0.63	1.51	1.41
Hydrocephaly	2.54	3.84	4.82	6.50	10.90	11.59	12.68
Anophthalmos	0.17	0.43	0.38	0.33	0.37	0.50	1.74
Microphthalmos	1.12	1.06	1.15	1.32	1.54	1.68	1.53
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	nr	nr	nr	nr	0.23*	0.36	0.38
Microtia	nr	nr	nr	nr	4.26*	4.05	6.09
Unspecified Anotia / Microtia	nr	nr	nr	nr	0.00*	0.10	0.10
Transposition of great vessels	0.10	0.30	0.60	0.56	0.78*	1.66	1.06
Tetralogy of Fallot	0.00	0.28	0.56	0.87	1.51	1.78	1.54
Hypoplastic left heart syndrome	0.00	0.03	0.00	0.31	0.45	1.19	1.22
Coarctation of aorta	0.14	0.05	0.27	0.54	0.86	1.02	0.53
Choanal atresia, bilateral	0.00	0.08	0.20	0.23	0.19	0.16	0.20
Cleft palate without cleft lip	2.91	3.32	3.44	3.46	3.93	4.55	4.91
Cleft lip with or without cleft palate	11.27	10.70	10.65	10.28	11.92	12.92	14.07
Oesophageal atresia / stenosis with or without fistula	1.89	2.19	2.51	2.90	3.04	3.69	3.62
Small intestine atresia / stenosis	0.34	1.36	1.49	1.61	2.04	2.59	3.12
Anorectal atresia / stenosis	2.44	3.82	3.41	4.35	4.80	5.27	5.54
Undescended testis (36 weeks of gestation or later)	1.39	2.31	4.36	4.63	5.05	6.29	8.45
Hypospadias	3.72	3.47	4.95	3.79	4.85	5.19	5.57
Epispadias	0.14	0.15	0.37	0.38	0.16	0.24	0.19
Indeterminate sex	0.91	1.61	2.21	1.71	1.88	2.12	2.69
Renal agenesis	0.41	0.53	0.77	1.19	2.13	2.42	2.57
Cystic kidney	0.58	0.65	1.36	1.74	3.04	4.37	3.69
Bladder exstrophy	0.07	0.18	0.30	0.28	0.30	0.34	0.30
Polydactyly, preaxial	3.18	2.26	2.39	2.63	2.82	3.52	4.11
‘Total Limb reduction defects (include unspecified)	3.48	5.43	5.17	5.02	5.99	6.43	7.87
Transverse	1.73	2.74	2.71	2.62	3.04	3.26	3.14
Preaxial	0.54	0.88	1.10	0.89	1.52	1.52	1.33
Postaxial	0.24	0.40	0.38	0.31	0.47	0.42	0.46
Intercalary	0.51	0.63	0.37	0.49	0.36	0.54	0.71
Mixed	0.37	0.65	0.50	0.60	0.45	0.49	1.76
Unspecified	0.10	0.13	0.11	0.12	0.15	0.18	0.46
Diaphragmatic hernia	0.64	1.13	1.46	2.02	2.96	3.87	3.61
Omphalocele	1.12	1.61	2.21	2.33	2.79	3.32	4.06
Gastroschisis	0.03	0.33	0.61	0.74	2.08	2.90	5.31
Unspecified Omphalocele / Gastroschisis	0.27	0.43	0.38	0.44	0.87	1.33	0.82
Prune belly sequence	0.00	0.38	0.61	0.74	1.03	1.23	0.74
Trisomy 13	0.14	0.30	0.55	0.42	0.76	0.96	0.68
Trisomy 18	0.24	0.35	0.95	0.93	1.41	2.16	1.60
Down syndrome, all ages (include age unknown)	14.38	14.98	14.79	15.76	16.85	19.11	19.05
<20	6.32	8.09	7.23	6.30	7.95	7.22	8.56
20-24	7.55	7.04	6.42	7.54	8.23	9.82	8.82
25-29	8.10	7.57	7.66	7.92	9.10	9.84	9.92
30-34	12.50	17.21	14.54	16.77	15.44	17.40	16.57
35-39	52.79	53.51	40.67	48.78	48.87	54.51	54.25
40-44	154.33	162.60	154.70	140.31	167.99	174.55	176.93
45+	254.37	366.24	242.50	285.39	275.08	377.48	374.06
unknown	---	---	---	---	---	---	---

nr = not reported
* data include less than 5 years

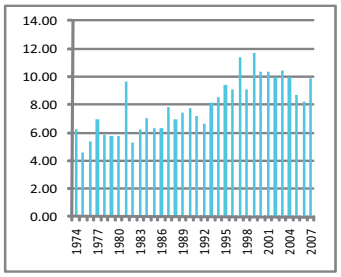
South America: ECLAMC

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

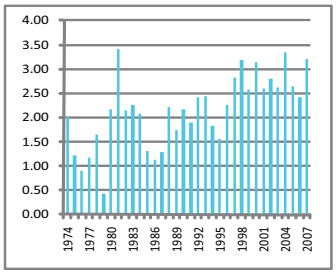
Anencephaly



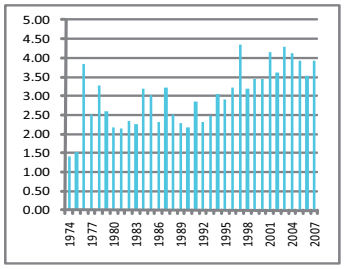
Spina Bifida



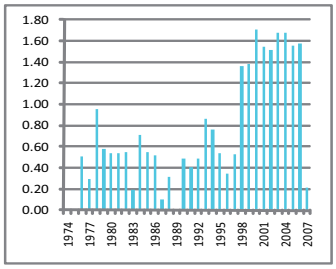
Encephalocele



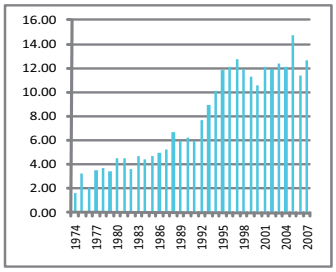
Microcephaly



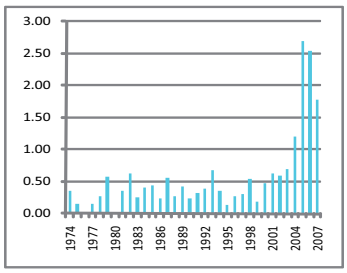
Holoprosencephaly



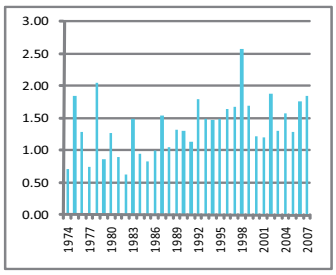
Hydrocephaly



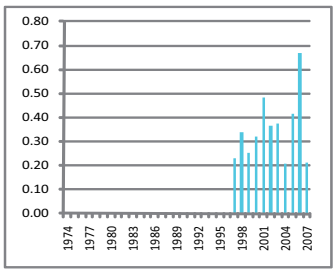
Anophthalmos



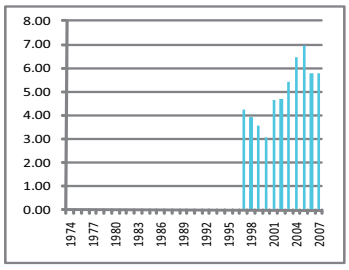
Microphthalmos



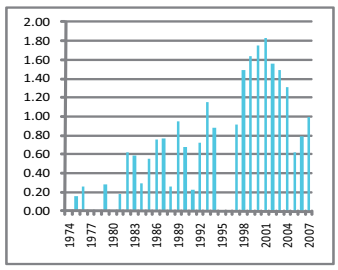
Anotia



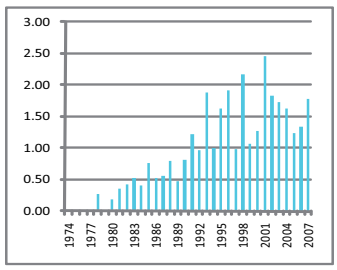
Microtia



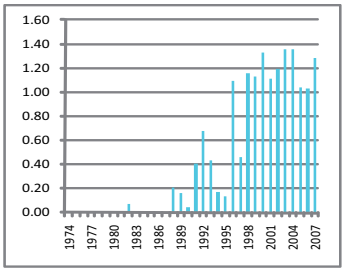
Transposition of great vessels



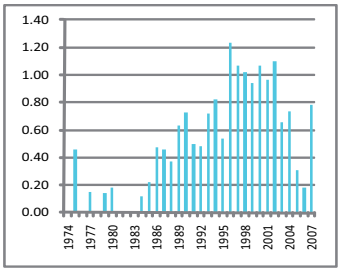
Tetralogy of Fallot



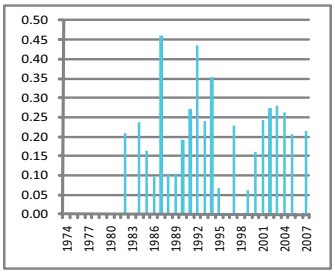
Hypoplastic left heart syndrome



Coarctation of aorta



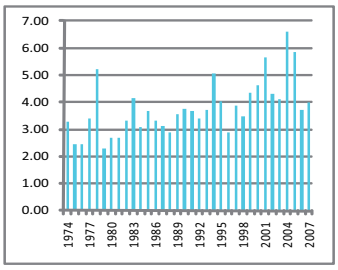
Choanal atresia, bilateral



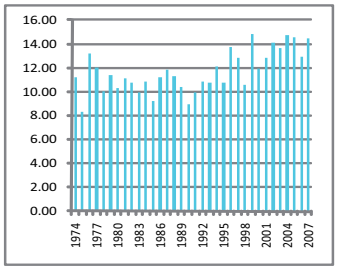
Note: L+S rates

South America: ECLAMC

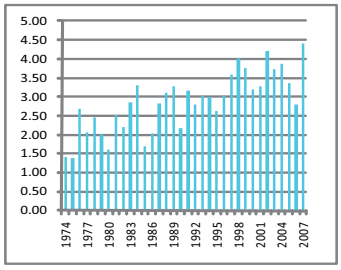
Cleft palate without cleft lip



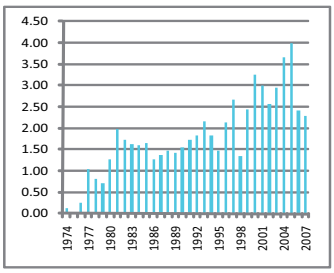
Cleft lip with or without cleft palate



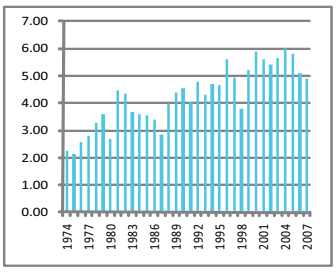
Oesophageal atresia/stenosis with or without fistula



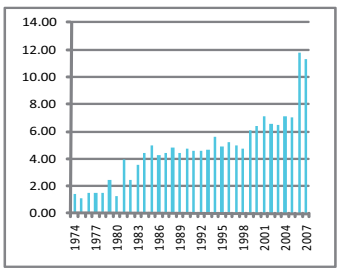
Small intestine atresia/stenosis



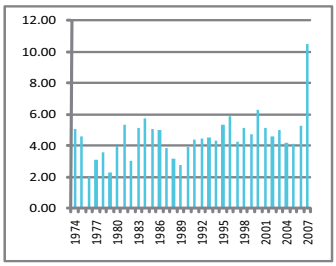
Anorectal atresia/stenosis



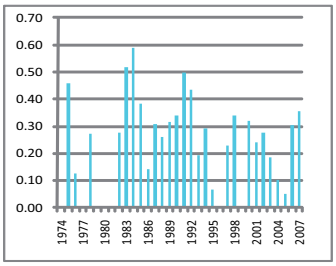
Undescended testis



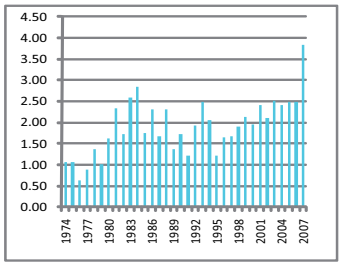
Hypospadias



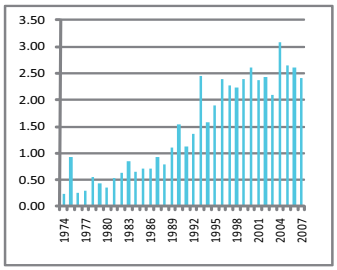
Epispadias



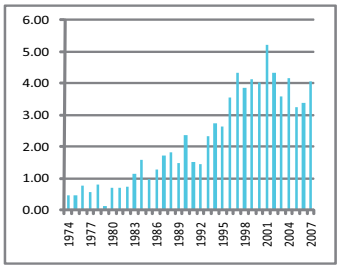
Indeterminate sex



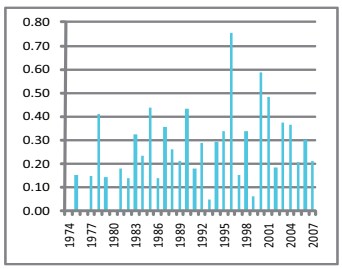
Renal agenesis



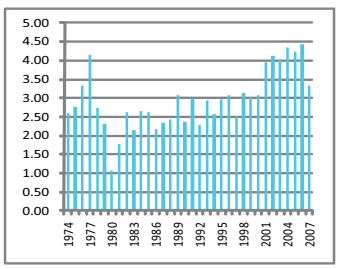
Cystic kidney



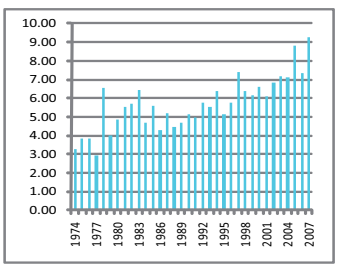
Bladder exstrophy



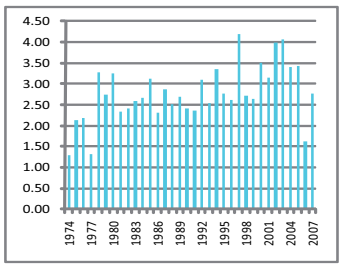
Polydactyly, preaxial



Limb reduction defects



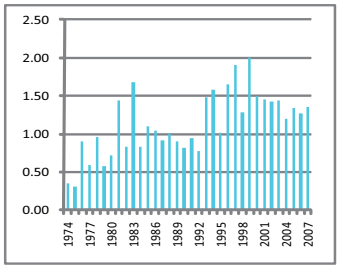
Limb reduction defects - transverse



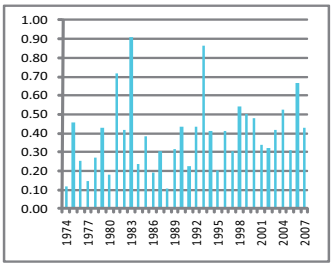
Note: L+S rates

South America: ECLAMC

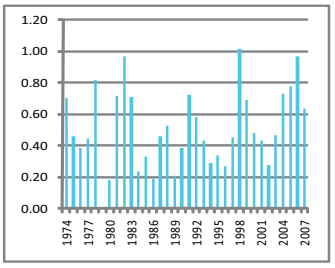
Limb reduction defects - preaxial



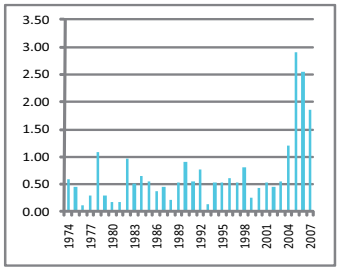
Limb reduction defects - postaxial



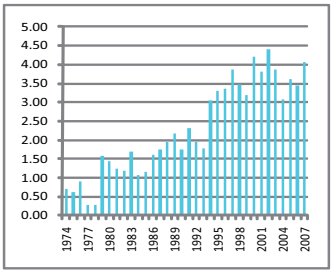
Limb reduction defects - intercalary



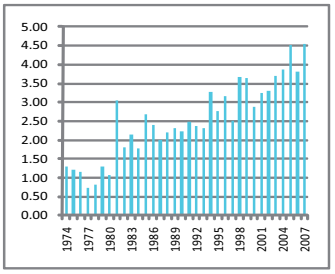
Limb reduction defects - mixed



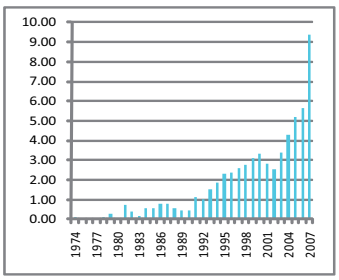
Diaphragmatic hernia



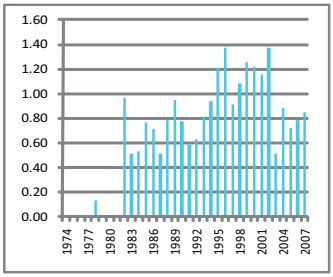
Omphalocele



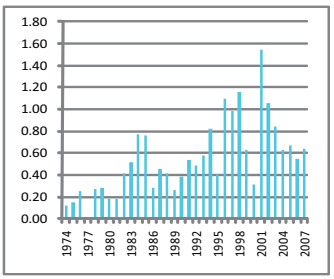
Gastroschisis



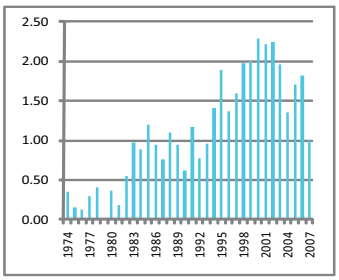
Prune belly sequence



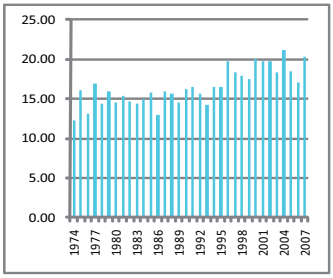
Trisomy 13



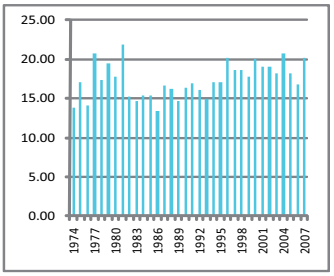
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



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. It 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 last year 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 surpasses 100,000, representing more than 21% 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.

Addresses and Staff:
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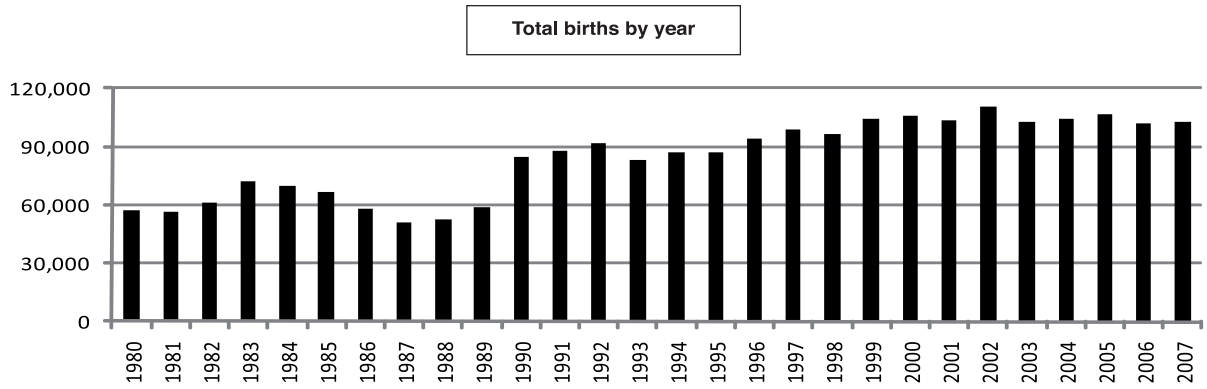
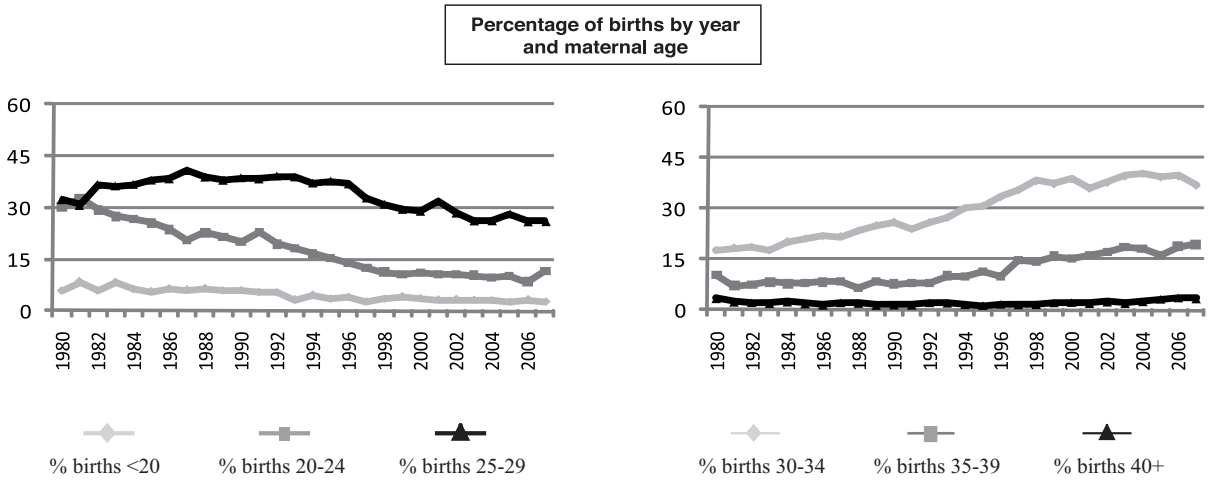
Professor of Biostatistics
Lecturer of the Department of Epidemiology & Population Health (Medical Statistics Unit)
London School of Hygiene &Tropical Medicine

Spain: ECEMC


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


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

Spain: ECEMC, 2007

Live births (LB)	102,139
Stillbirths (SB)	401
Total births	102,540
Number of terminations of pregnancy (ToP) for birth defects	nr

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	3	5	nr	0.78
Spina bifida	8	0	nr	0.78
Encephalocele	3	0	nr	0.29
Microcephaly	11	0	nr	1.07
Holoprosencephaly	4	0	nr	0.39
Hydrocephaly	19	2	nr	2.05
Anophthalmos	1	0	nr	0.10
Microphthalmos	7	0	nr	0.68
Unspecified Anophthalmos/Microphthalmos	0	0	nr	0.00
Anotia	0	0	nr	0.00
Microtia	21	0	nr	2.05
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	7	0	nr	0.68
Tetralogy of Fallot	7	1	nr	0.78
Hypoplastic left heart syndrome	2	0	nr	0.20
Coarctation of aorta	7	0	nr	0.68
Choanal atresia, bilateral	4	0	nr	0.39
Cleft palate without cleft lip	34	0	nr	3.32
Cleft lip with or without cleft palate	34	2	nr	3.51
Oesophageal atresia/stenosis with or without fistula	14	0	nr	1.37
Small intestine atresia/stenosis	8	0	nr	0.78
Anorectal atresia/stenosis	19	0	nr	1.85
Undescended testis (36 weeks of gestation or later)	24	0	nr	2.34
Hypospadias	17	0	nr	1.66
Epispadias	0	0	nr	0.00
Indeterminate sex	1	0	nr	0.10
Renal agenesis	0	0	nr	0.00
Cystic kidney	16	1	nr	1.66
Bladder exstrophy	4	0	nr	0.39
Polydactyly, preaxial	21	1	nr	2.15
Total Limb reduction defects (include unspecified)	45	2	nr	4.58
Transverse	20	2	nr	2.15
Preaxial	6	0	nr	0.59
Postaxial	1	0	nr	0.10
Intercalary	2	0	nr	0.20
Mixed	11	0	nr	1.07
Unspecified	5	0	nr	0.49
Diaphragmatic hernia	21	0	nr	2.05
Omphalocele	6	2	nr	0.78
Gastroschisis	5	2	nr	0.68
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	2	0	nr	0.20
Trisomy 13	2	0	nr	0.20
Trisomy 18	3	4	nr	0.68
Down syndrome, all ages (include age unknown)	82	1	nr	8.09
<20	3	0	nr	11.62
20-24	6	0	nr	5.06
25-29	13	0	nr	4.86
30-34	26	0	nr	6.87
35-39	27	0	nr	13.56
40-44	6	1	nr	21.00
45+	1	0	nr	52.36
unknown	0	0	nr	---

nr = not reported

Spain: ECEMC, Previous years rates 1980 - 2007

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

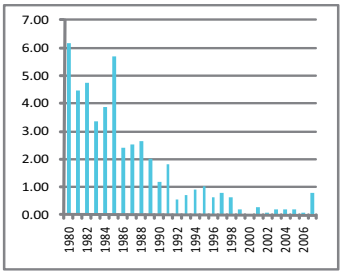
	1974-1977	1978-1982*	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**174,345**	**317,341**	**375,426**	**450,525**	**521,018**	**518,325**	
Anencephaly	5.10	3.66	1.52	0.82	0.23	0.29	
Spina bifida	4.19	4.76	4.16	2.66	1.59	1.10	
Encephalocele	1.38	0.76	0.99	0.49	0.19	0.19	
Microcephaly	2.29	1.92	2.18	1.98	1.48	0.98	
Holoprosencephaly	0.34	0.54	0.53	0.55	0.33	0.31	
Hydrocephaly	2.75	2.30	2.96	2.77	2.13	1.95	
Anophthalmos	0.69	0.63	0.29	0.22	0.13	0.15	
Microphthalmos	1.66	2.08	1.86	1.46	1.13	0.85	
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	
Anotia	0.00	0.03	0.05	0.22	0.08	0.10	
Microtia	1.89	2.05	1.52	1.49	1.54	1.39	
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	
Transposition of great vessels	0.46	0.79	1.33	1.49	1.06	1.27	
Tetralogy of Fallot	0.17	0.22	0.93	1.15	1.07	0.83	
Hypoplastic left heart syndrome	0.34	0.38	0.77	0.62	0.40	0.29	
Coarctation of aorta	0.52	0.25	0.75	0.91	0.71	0.79	
Choanal atresia, bilateral	0.17	0.16	0.40	0.22	0.13	0.23	
Cleft palate without cleft lip	5.16	4.60	4.95	4.37	3.78	3.94	
Cleft lip with or without cleft palate	5.74	5.77	5.73	4.99	3.69	3.74	
Oesophageal atresia / stenosis with or without fistula	2.29	2.11	2.02	1.91	1.63	2.06	
Small intestine atresia / stenosis	0.52	0.57	0.56	0.42	0.50	0.56	
Anorectal atresia / stenosis	2.47	2.49	1.97	2.13	2.17	1.93	
Undescended testis (36 weeks of gestation or later)	1.72	2.14	2.64	2.89	2.63	2.24	
Hypospadias	2.81	2.49	2.32	1.51	2.26	1.62	
Epispadias	0.29	0.19	0.24	0.09	0.10	0.04	
Indeterminate sex	0.75	1.10	1.01	0.62	0.59	0.42	
Renal agenesis	0.57	0.82	0.75	0.64	0.12	0.08	
Cystic kidney	1.32	1.20	1.65	1.80	1.50	1.62	
Bladder exstrophy	0.23	0.28	0.27	0.31	0.21	0.23	
Polydactyly, preaxial	2.47	2.55	3.14	2.71	2.26	2.37	
'Total Limb reduction defects (include unspecified)	7.86	6.33	7.01	6.33	4.95	4.65	
Transverse	3.10	2.84	2.90	2.24	2.05	1.87	
Preaxial	1.09	1.29	0.96	0.69	0.63	0.62	
Postaxial	0.17	0.13	0.11	0.33	0.13	0.10	
Intercalary	0.63	0.38	0.43	0.42	0.25	0.25	
Mixed	1.38	0.79	1.25	1.04	1.02	0.96	
Unspecified	1.49	0.91	1.36	1.60	0.86	0.41	
Diaphragmatic hernia	2.81	2.33	2.16	1.98	0.90	0.98	
Omphalocele	2.01	1.58	1.15	1.09	0.52	0.62	
Gastroschisis	0.75	0.38	0.45	0.38	0.35	0.56	
Unspecified Omphalocele / Gastroschisis	0.34	0.41	0.21	0.11	0.02	0.02	
Prune belly sequence	0.52	0.60	0.64	0.31	0.17	0.23	
Trisomy 13	0.29	0.47	0.32	0.64	0.35	0.33	
Trisomy 18	0.63	1.29	1.15	0.60	0.61	0.66	
Down syndrome, all ages (include age unknown)	14.80	14.97	13.42	11.56	9.14	7.31	
<20	7.79	6.75	10.85	1.91	1.66	5.48	
20-24	8.59	5.03	5.42	5.55	4.78	5.19	
25-29	5.84	7.58	7.46	6.86	5.50	3.98	
30-34	11.06	13.02	14.70	12.20	8.06	6.39	
35-39	44.64	44.49	41.73	27.12	16.75	11.55	
40-44	139.08	190.28	87.08	58.65	48.21	27.85	
45+	116.05	244.23	264.03	365.85	183.49	48.45	
unknown	---	---	---	---	---	---	

nr = not reported
* data include less than 5 years

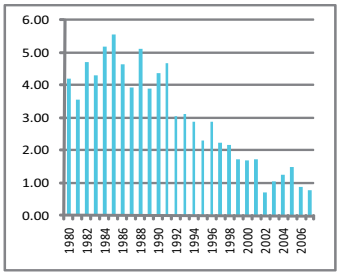
Spain: ECEMC

'Time trends 1980-2007 (Birth prevalence rates per 10,000)

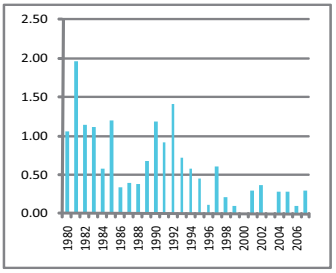
Anencephaly



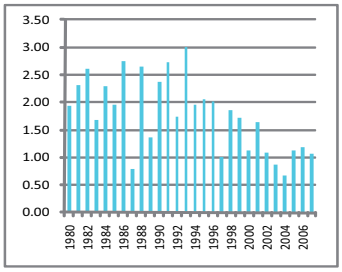
Spina Bifida



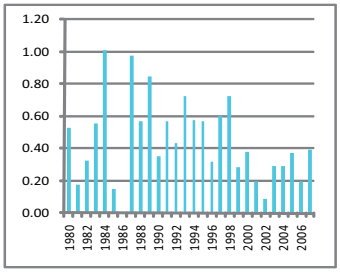
Encephalocele



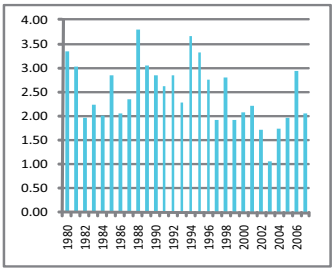
Microcephaly



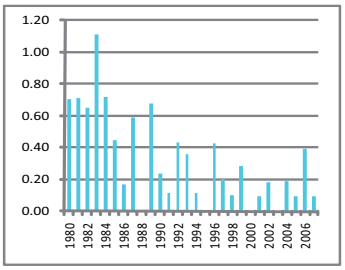
Holoprosencephaly



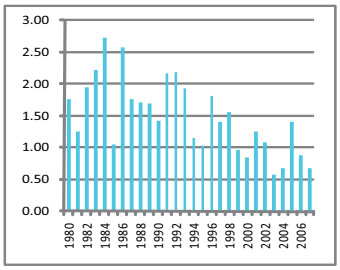
Hydrocephaly



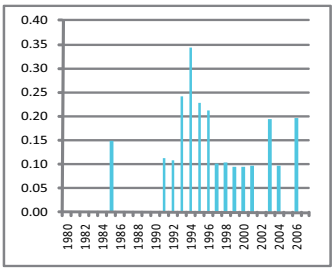
Anophthalmos



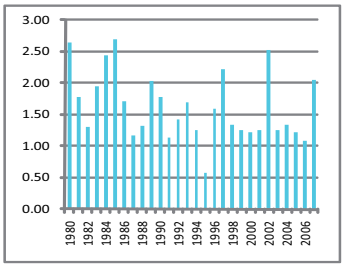
Microphthalmos



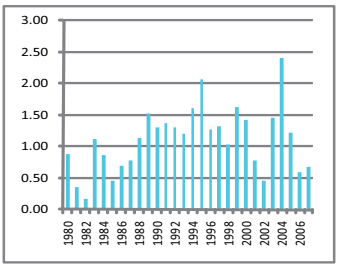
Anotia



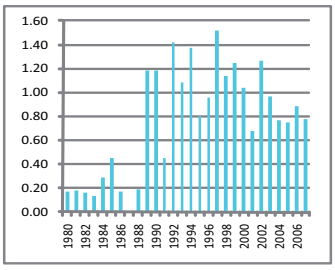
Microtia



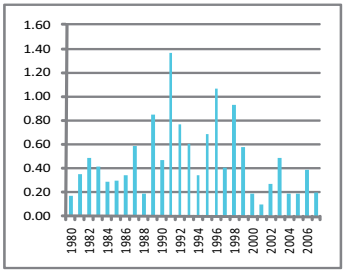
Transposition of great vessels



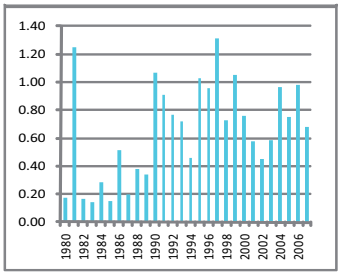
Tetralogy of Fallot



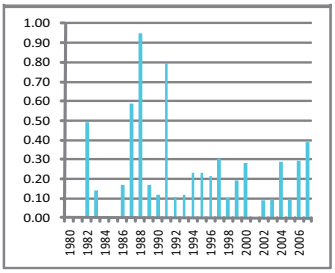
Hypoplastic left heart syndrome



Coarctation of aorta



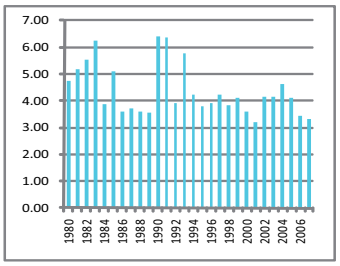
Choanal atresia, bilateral



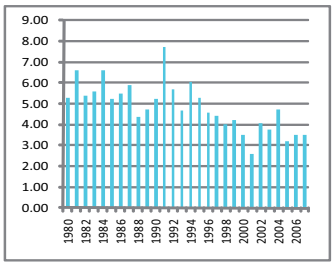
Note: L+S rates

Spain: ECEMC

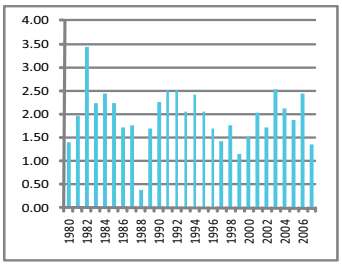
Cleft palate without cleft lip



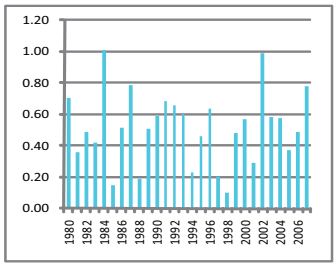
Cleft lip with or without cleft palate



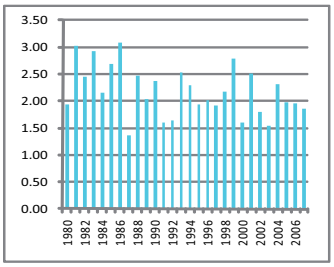
Oesophageal atresia/stenosis with or without fistula



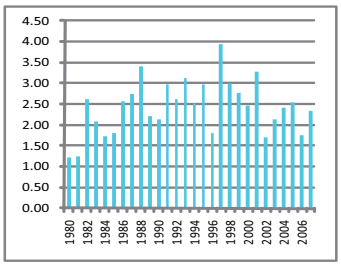
Small intestine atresia/stenosis



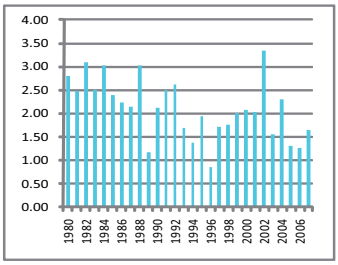
Anorectal atresia/stenosis



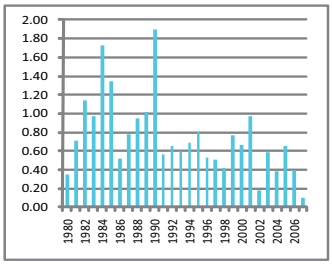
Undescended testis



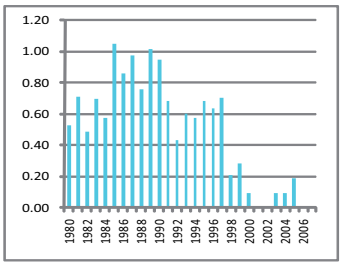
Hypospadias



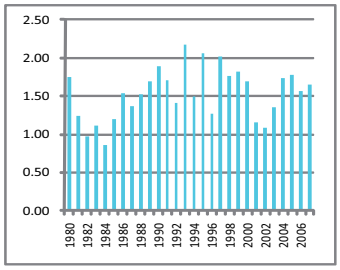
Indeterminate sex



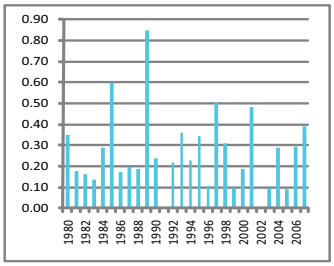
Renal agenesis



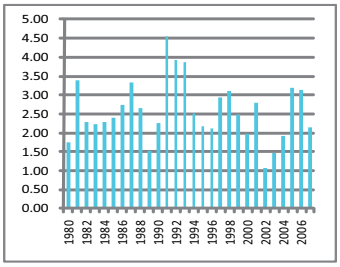
Cystic kidney



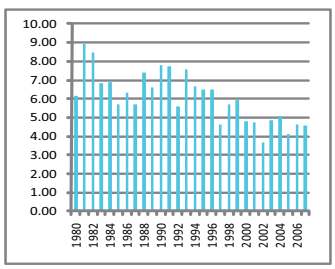
Bladder exstrophy



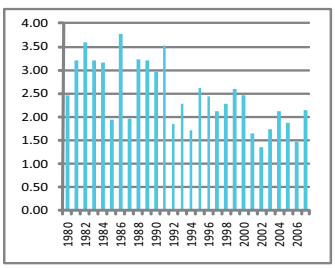
Polydactyly, preaxial



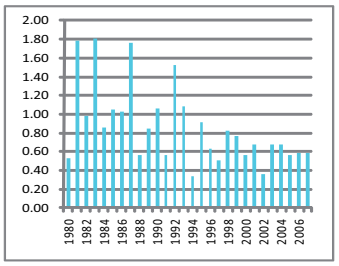
Limb reduction defects



Limb reduction defects - transverse



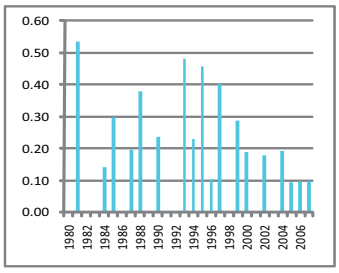
Limb reduction defects - preaxial



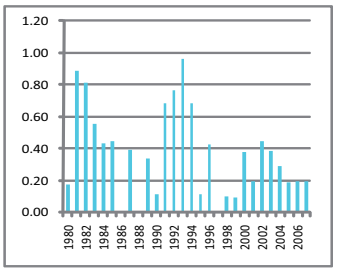
Note: L+S rates

Spain: ECEMC

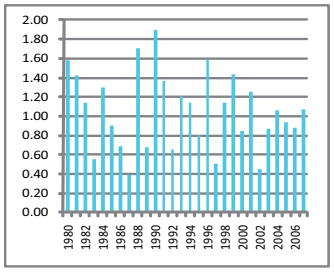
Limb reduction defects - postaxial



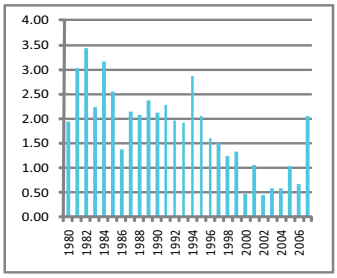
Limb reduction defects - intercalary



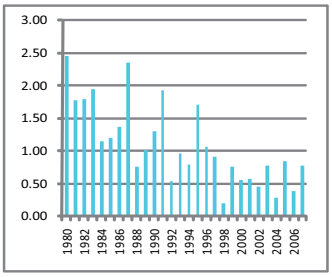
Limb reduction defects - mixed



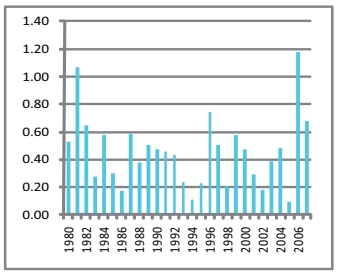
Diaphragmatic hernia



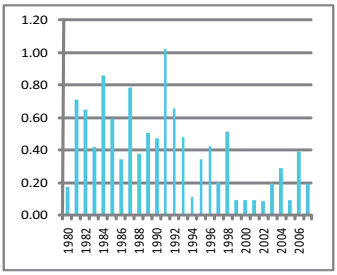
Omphalocele



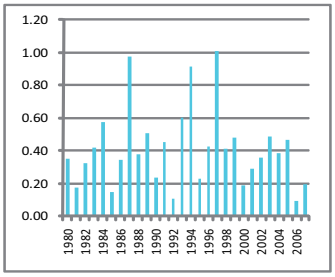
Gastroschisis



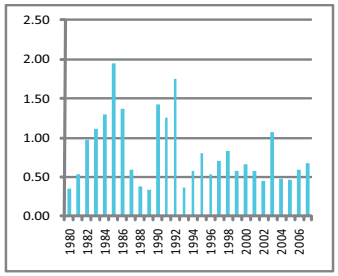
Prune belly sequence



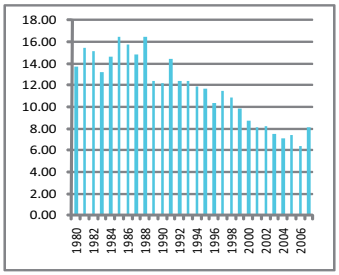
Trisomy 13



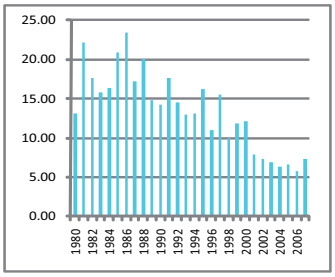
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates

Sweden

The Swedish Registry of Congenital Malformations and the Medical Birth Registry.

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

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

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

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

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

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

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Phone: 46-8-752443899
Fax: 46-8-752473176
E-mail: karin.gottvall@socialstyrelsen.se

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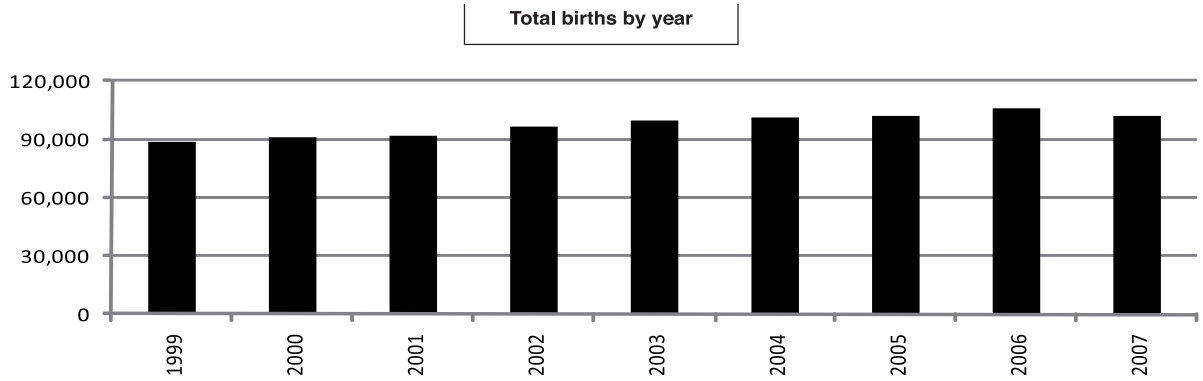
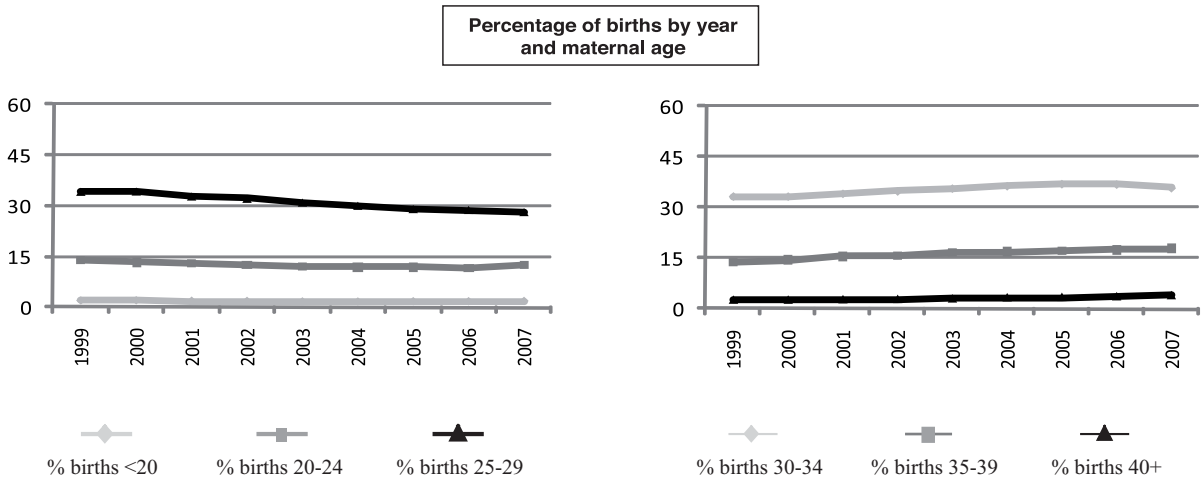
Phone: 46-18-6115942
Fax: 46-18-554025
E-Mail: goran.anneren@genpat.uu.se

Sweden





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	101	91.0	Cystic kidney	49	39.8
Spina bifida	94	67.1	Limb reduction defects	39	25.8
Encephalocele	29	82.9	Diaphragmatic hernia	49	49.0
Holoprosencephaly	26	78.8	Omphalocele	55	68.8
Hydrocephaly	80	74.8	Gastroschisis	13	24.1
Hypoplastic left heart syndrome	44	58.7	Trisomy 13	64	69.6
Cleft palate without cleft lip	9	5.0	Trisomy 18	229	81.5
Cleft lip with or without cleft palate	18	7.9	Down syndrome	424	50.2
Renal agenesis	26	56.5			

Total ToPs with births defects = 1,530 (Ratio ToPs/Births: 4.94 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Sweden: 2007

Live births (LB)	101,435
Stillbirths (SB)	253
Total births	101,688
Number of terminations of pregnancy (ToP) for birth defects	520

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	2	0	30	3.15
Spina bifida	16	0	34	4.92
Encephalocele	2	0	12	1.38
Microcephaly	2	0	1	0.30
Holoprosencephaly	3	0	3	0.59
Hydrocephaly	11	0	28	3.84
Anophthalmos	2	0	0	0.20
Microphthalmos	0	0	0	0.00
Unspecified Anophthalmos/Microphthalmos	2	0	0	0.20
Anotia	6	0	0	0.59
Microtia	5	0	0	0.49
Unspecified Anotia/Microtia	1	0	0	0.10
Transposition of great vessels	36	0	2	3.74
Tetralogy of Fallot	26	0	1	2.66
Hypoplastic left heart syndrome	9	0	16	2.46
Coarctation of aorta	53	0	3	5.51
Choanal atresia, bilateral	2	0	0	0.20
Cleft palate without cleft lip	55	0	3	5.70
Cleft lip with or without cleft palate	0	4	0	0.39
Oesophageal atresia/stenosis with or without fistula	17	0	2	1.87
Small intestine atresia/stenosis	11	0	2	1.28
Anorectal atresia/stenosis	23	0	1	2.36
Undescended testis (36 weeks of gestation or later)	0	0	0	0.00
Hypospadias	212	0	1	20.95
Epispadias	0	0	0	0.00
Indeterminate sex	1	0	1	0.20
Renal agenesis	13	1	12	2.56
Cystic kidney	24	0	11	3.44
Bladder exstrophy	3	0	0	0.30
Polydactyly, preaxial	17	0	2	1.87
Total Limb reduction defects (include unspecified)	43	0	11	5.31
Transverse	34	0	5	3.84
Preaxial	4	0	3	0.69
Postaxial	1	0	1	0.20
Intercalary	2	0	2	0.39
Mixed	3	0	1	0.39
Unspecified	19	0	6	2.46
Diaphragmatic hernia	19	0	16	3.44
Omphalocele	6	0	12	1.77
Gastroschisis	13	0	4	1.67
Unspecified Omphalocele/Gastroschisis	nr	nr	nr	nr
Prune belly sequence	0	0	4	0.39
Trisomy 13	9	0	18	2.66
Trisomy 18	20	2	75	9.54
Down syndrome, all ages (include age unknown)	121	0	147	26.36
<20	3	0	1	22.57
20-24	8	0	2	7.81
25-29	27	0	6	11.63
30-34	36	0	27	17.37
35-39	28	0	60	48.69
40-44	12	0	46	153.56
45+	0	0	3	171.43
unknown	7	0	2	---

nr = not reported

Sweden: Previous years rates 1999 - 2007

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

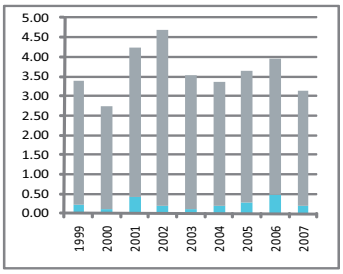
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002*	2003-2007
Total births						**367,290**	**510,344**
Anencephaly						3.78	3.53
Spina bifida						5.15	4.15
Encephalocele						1.01	1.16
Microcephaly						0.35	0.25
Holoprosencephaly						0.93	0.98
Hydrocephaly						3.19	3.57
Anophthalmos						0.19	0.16
Microphthalmos						0.33	0.47
Unspecified Anophthalmos / Microphthalmos						0.00	0.05
Anotia						1.01	0.96
Microtia						0.08	0.25
Unspecified Anotia / Microtia						0.00	0.02
Transposition of great vessels						3.48	3.63
Tetralogy of Fallot						2.48	3.15
Hypoplastic left heart syndrome						2.04	2.51
Coarctation of aorta						3.68	5.17
Choanal atresia, bilateral						0.63	0.43
Cleft palate without cleft lip						5.88	5.27
Cleft lip with or without cleft palate						10.05	8.46
Oesophageal atresia / stenosis with or without fistula						2.10	2.59
Small intestine atresia / stenosis						2.10	2.65
Anorectal atresia / stenosis						3.10	2.63
Undescended testis (36 weeks of gestation or later)						nr	0.00*
Hypospadias						20.94	20.91
Epispadias						0.19	0.14
Indeterminate sex						0.33	0.20
Renal agenesis						2.18	1.33
Cystic kidney						2.97	3.70
Bladder exstrophy						0.25	0.27
Polydactyly, preaxial						4.11	4.66
‘Total Limb reduction defects (include unspecified)						4.90	5.09
Transverse						3.46	3.33
Preaxial						0.25	0.47
Postaxial						0.14	0.16
Intercalary						0.19	0.27
Mixed						0.87	0.51
Unspecified						0.00	0.61
Diaphragmatic hernia						2.53	3.19
Omphalocele						2.42	2.66
Gastroschisis						1.85	1.80
Unspecified Omphalocele / Gastroschisis						nr	nr
Prune belly sequence						0.11	0.16
Trisomy 13						1.93	2.94
Trisomy 18						5.55	8.21
Down syndrome, all ages (include age unknown)						23.33	26.65
<20						8.84	13.03
20-24						8.04	10.11
25-29						8.48	10.24
30-34						16.75	17.79
35-39						52.68	55.90
40-44						170.45	166.01
45+						472.44	345.32
unknown						---	---

nr = not reported
* data include less than 5 years

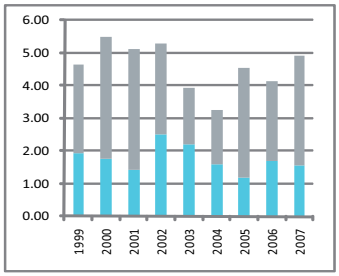
Sweden

'Time trends 1999-2007 (Birth prevalence rates per 10,000)

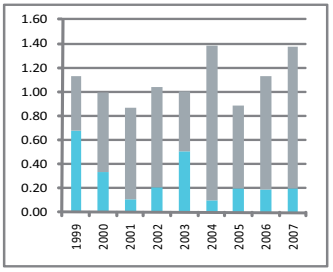
Anencephaly



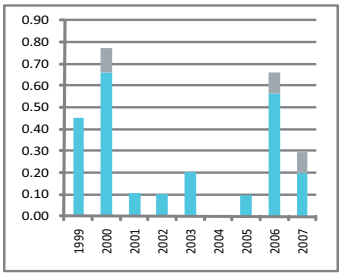
Spina Bifida



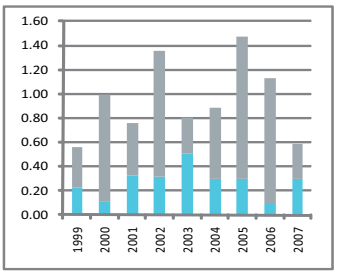
Encephalocele



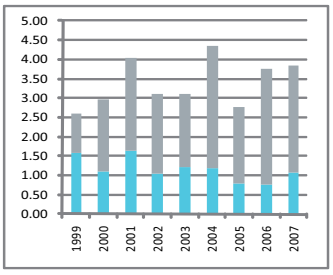
Microcephaly



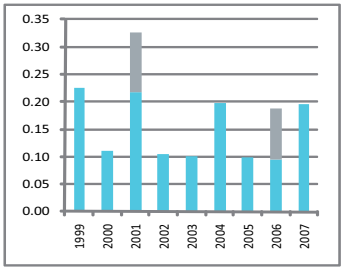
Holoprosencephaly



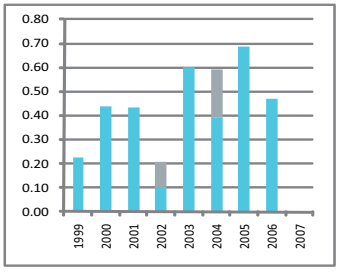
Hydrocephaly



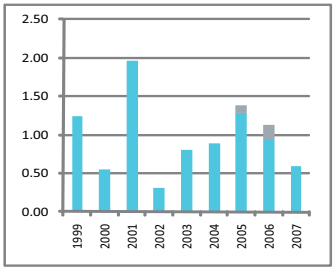
Anophthalmos



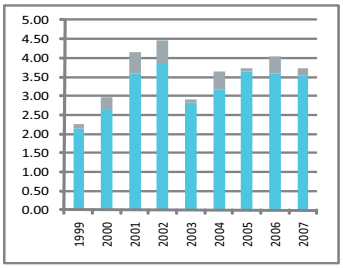
Microphthalmos



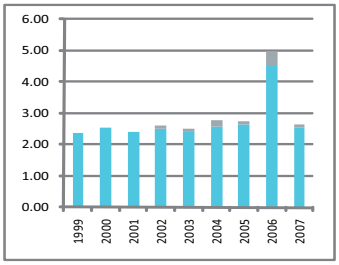
Anotia



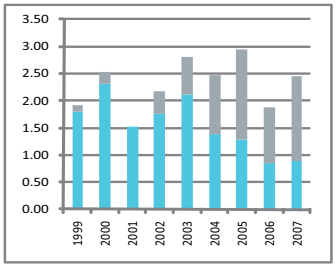
Transposition of great vessels



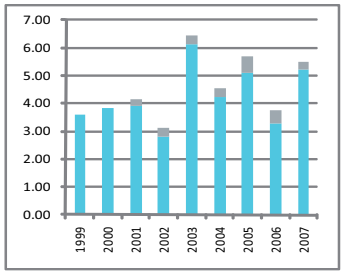
Tetralogy of Fallot



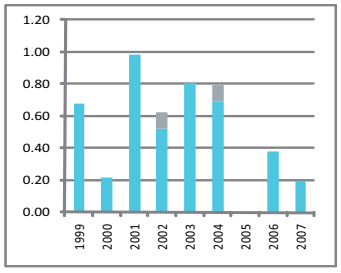
Hypoplastic left heart syndrome



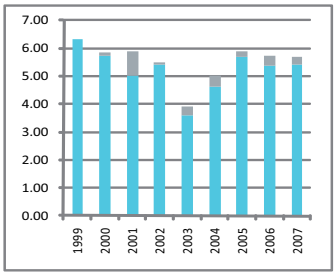
Coarctation of aorta



Choanal atresia, bilateral



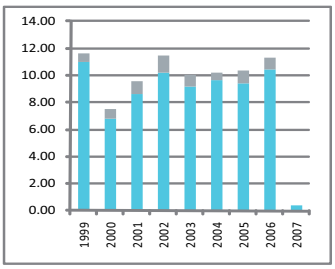
Cleft palate without cleft lip



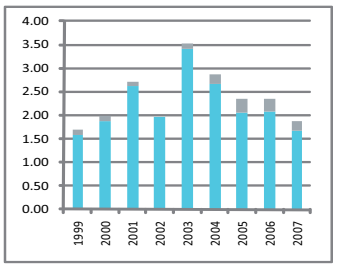
Note: L+S rates, ToP rates

Sweden

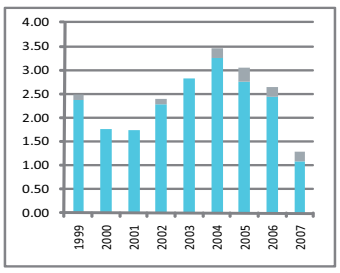
Cleft lip with or without cleft palate



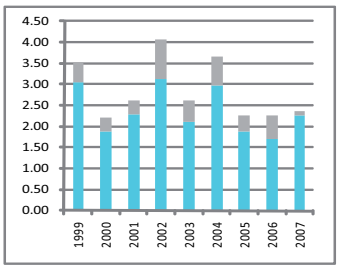
Oesophageal atresia/stenosis with or without fistula



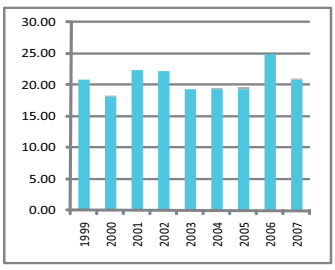
Small intestine atresia/stenosis



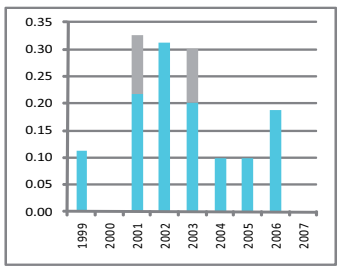
Anorectal atresia/stenosis



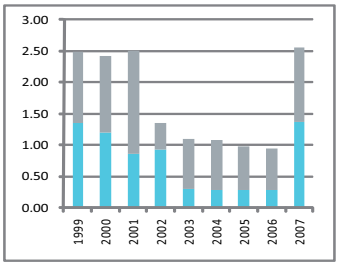
Hypospadias



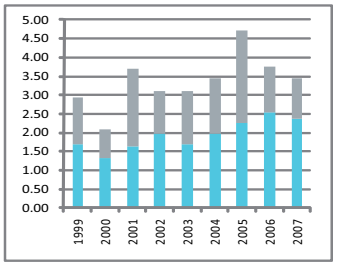
Epispadias



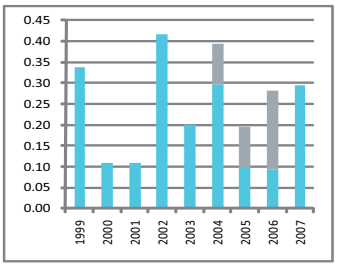
Renal agenesis



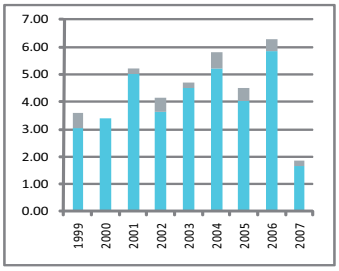
Cystic kidney



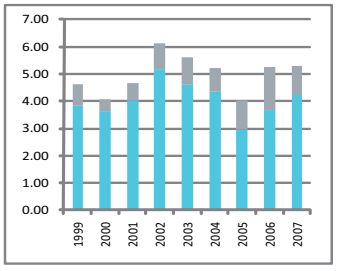
Bladder exstrophy



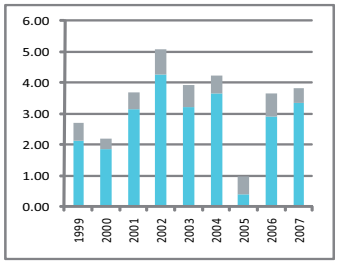
Polydactyly, preaxial



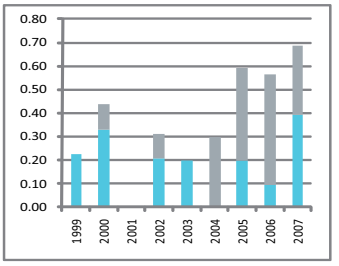
Limb reduction defects



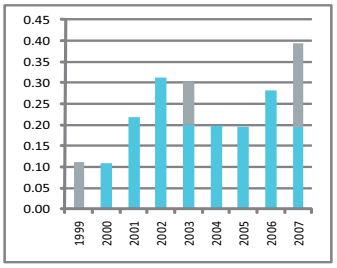
Limb reduction defects - transverse



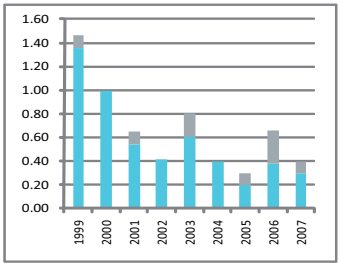
Limb reduction defects - preaxial



Limb reduction defects - intercalary



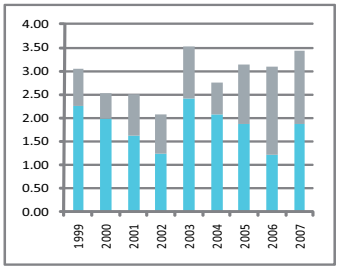
Limb reduction defects - mixed



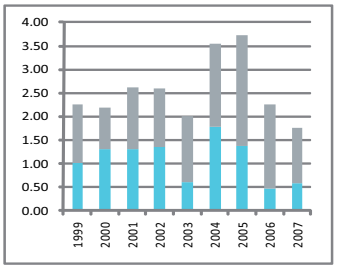
Note: L+S rates, ToP rates

Sweden

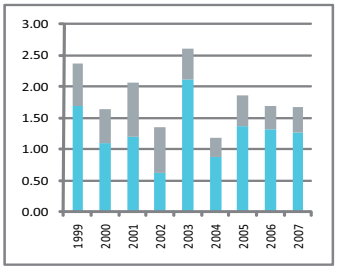
Diaphragmatic hernia



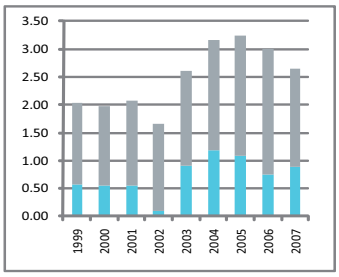
Omphalocele



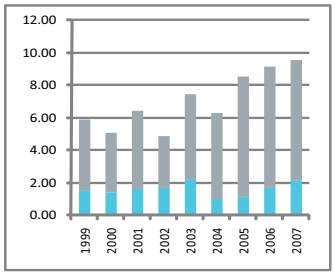
Gastroschisis



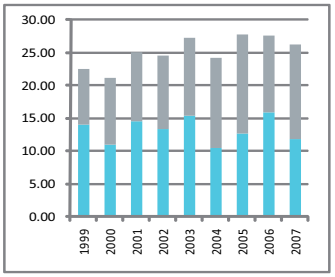
Trisomy 13



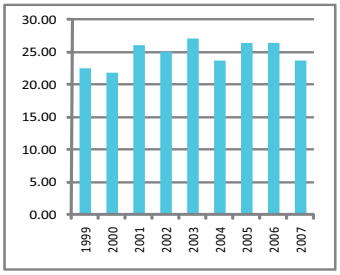
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

Ukraine: OMNI-Net
Ukraine Birth Defects Program

History:
Population based birth defects surveillance began in 2000 in the framework of the Ukrainian-American Birth Defects Program (UABDP) funded by the United States Agency for International Development (USAID). The program became an associate member of ICBDRS in 2001. In 2005 the USAID financing of surveillance finally ended and the program was assumed by OMNI-Net, a not-for-profit international organization incorporated in Ukraine. OMNI-Net represents five resource OMNI-centers conducting birth defects surveillance, providing care for children and promoting prevention programs with participation of parental organizations, 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.

Size and coverage:
Birth defects surveillance concerns 25000 births in two oblasts (provinces) of Northwest of Ukraine, representing approximately 5% of births in Ukraine. The population is relatively homogeneous, stable (data is pooled from two oblasts). The northern counties (rayons) of both oblasts are contaminated from Chornobyl disaster.

Legislation and funding:
OMNI-Net personnel are financed by the Ukrainian Ministry of Health and oblast authorities. 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.

Sources of ascertainment:
Relevant hospital admission/discharge summaries are systematically reviewed. Data from specialty clinics, laboratories and other services are explored. Pregnancy, obstetrics, delivery, neonatal and pediatrics records are considered.

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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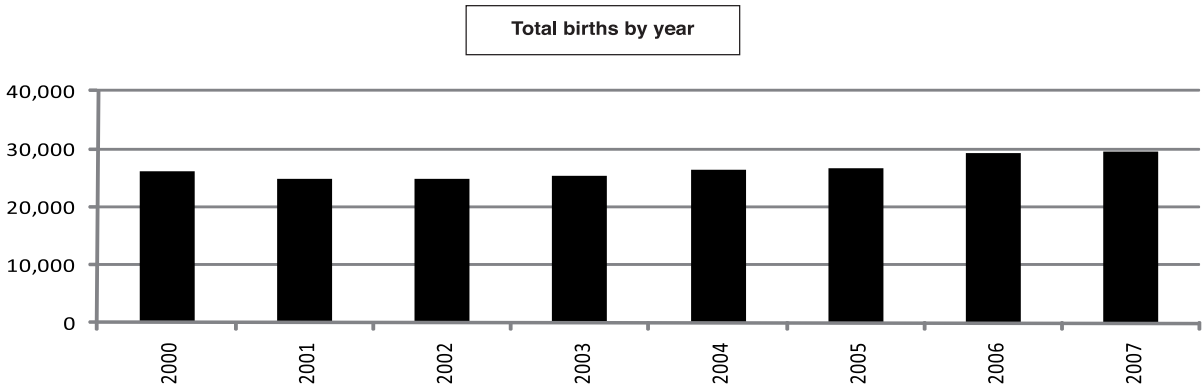
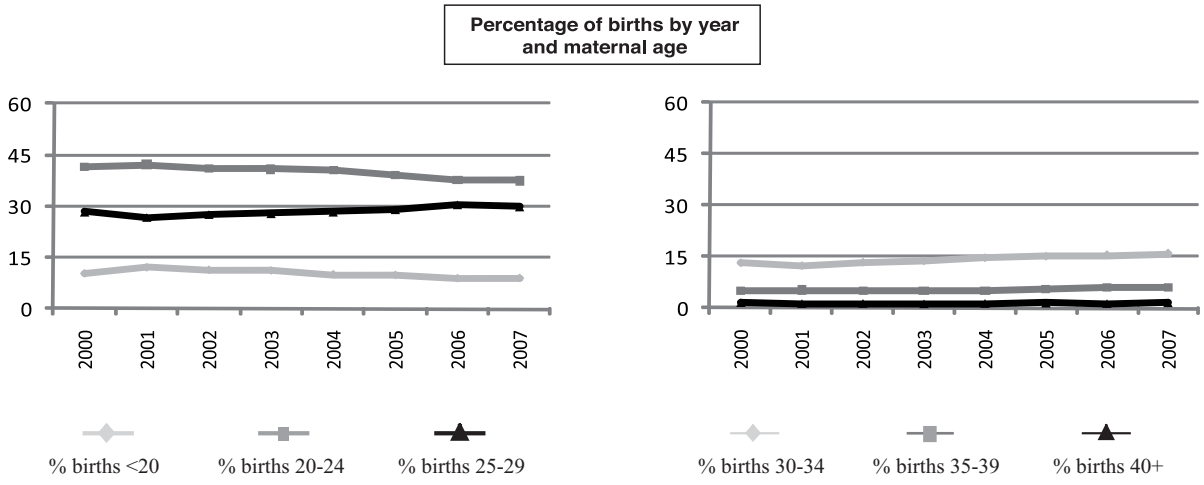
E-mail: rivneomni@gmail.com
yevtushokl@gmail.com

Ukraine: OMNI-Net





Ukraine: OMNI-Net, 2007

Live births (LB)	29,304
Stillbirths (SB)	175
Total births	29,479
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	5	17	7.80
Spina bifida	13	2	12	9.16
Encephalocele	1	1	4	2.04
Microcephaly (1)	11	0	nr	3.73
Holoprosencephaly	5	2	nr	2.37
Hydrocephaly	13	6	nr	6.45
Anophthalmos (1)	1	0	nr	0.34
Microphthalmos (1)	3	1	nr	1.36
Unspecified Anophthalmos/Microphthalmos	1	0	nr	0.34
Anotia	1	0	nr	0.34
Microtia	6	0	nr	2.04
Unspecified Anotia/Microtia	0	0	nr	0.00
Transposition of great vessels	10	0	nr	3.39
Tetralogy of Fallot	8	1	nr	3.05
Hypoplastic left heart syndrome	0	2	nr	0.68
Coarctation of aorta	9	0	nr	3.05
Choanal atresia, bilateral	0	0	nr	0.00
Cleft palate without cleft lip	16	0	nr	5.43
Cleft lip with or without cleft palate	16	1	nr	5.77
Oesophageal atresia/stenosis with or without fistula	7	0	nr	2.37
Small intestine atresia/stenosis	8	0	nr	2.71
Anorectal atresia/stenosis	4	0	nr	1.36
Undescended testis (36 weeks of gestation or later)	91	0	nr	30.87
Hypospadias (2)	8	0	nr	2.71
Epispadias	0	0	nr	0.00
Indeterminate sex	0	0	nr	0.00
Renal agenesis	3	0	nr	1.02
Cystic kidney	13	0	nr	4.41
Bladder exstrophy	2	0	nr	0.68
Polydactyly, preaxial	14	1	nr	5.09
Total Limb reduction defects (include unspecified)	14	1	nr	5.09
Transverse	7	0	nr	2.37
Preaxial	3	1	nr	1.36
Postaxial	1	0	nr	0.34
Intercalary	1	0	nr	0.34
Mixed	2	0	nr	0.68
Unspecified	0	0	nr	0.00
Diaphragmatic hernia	6	1	nr	2.37
Omphalocele	4	3	nr	2.37
Gastroschisis	4	0	nr	1.36
Unspecified Omphalocele/Gastroschisis	0	0	nr	0.00
Prune belly sequence	0	0	nr	0.00
Trisomy 13 (1)	0	1	nr	0.34
Trisomy 18 (1, 4)	1	0	nr	0.34
Down syndrome, all ages (include age unknown) (1, 3)	47	1	nr	16.28
<20	3	0	nr	11.40
20-24	8	0	nr	7.25
25-29	12	0	nr	13.60
30-34	10	1	nr	23.41
35-39	7	0	nr	39.26
40-44	6	0	nr	134.83
45+	1	0	nr	263.16
unknown	0	0	nr	---

nr = not reported
(1) Clinical diagnosis only; with photodocumentation or measurements documented
(2) Includes penile, scrotal, and perineal hypospadias only
(3) One ToP with Down Syndrome confirmed by amniocentesis (maternal age: 41 year fetal karyotype: 47, XX, +21)
(4) One ToP with Trisomy 18 confirmed by amniocentesis (maternal age: 29 years; fetal karyotype: 47, XY +18)

Ukraine: OMNI-Net, Previous years rates 2000 - 2007

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

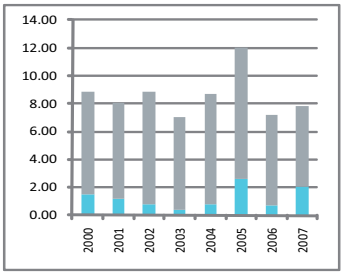
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002*	2003-2007
Total births						**75,691**	**137,134**
Anencephaly						8.59	8.53
Spina bifida						9.91	11.30
Encephalocele						2.25	2.04
Microcephaly						2.91	3.14
Holoprosencephaly						0.00	1.24
Hydrocephaly						6.08	5.76
Anophthalmos						0.13	0.07
Microphthalmos						1.32	1.02
Unspecified Anophthalmos / Microphthalmos						0.00	0.07
Anotia						0.26	0.44
Microtia						1.32	2.11
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						4.10	3.28
Tetralogy of Fallot						1.98	2.26
Hypoplastic left heart syndrome						0.53	1.39
Coarctation of aorta						0.66	1.97
Choanal atresia, bilateral						0.00	0.00
Cleft palate without cleft lip						4.36	4.67
Cleft lip with or without cleft palate						9.38	8.09
Oesophageal atresia / stenosis with or without fistula						1.59	2.19
Small intestine atresia / stenosis						1.72	1.68
Anorectal atresia / stenosis						2.51	2.11
Undescended testis (36 weeks of gestation or later)						38.97	39.01
Hypospadias						3.57	3.14
Epispadias						0.53	0.07
Indeterminate sex						0.66	0.29
Renal agenesis						0.92	0.73
Cystic kidney						0.92	3.57
Bladder exstrophy						0.79	0.73
Polydactyly, preaxial						3.70	3.57
‘Total Limb reduction defects (include unspecified)						4.36	3.21
Transverse						2.25	1.82
Preaxial						0.53	0.58
Postaxial						0.40	0.22
Intercalary						0.40	0.29
Mixed						0.26	0.29
Unspecified						0.53	0.00
Diaphragmatic hernia						2.11	1.75
Omphalocele						1.32	1.46
Gastroschisis						1.06	1.53
Unspecified Omphalocele / Gastroschisis						0.00	0.00
Prune belly sequence						0.00	0.00
Trisomy 13						0.26	0.36
Trisomy 18						0.40	0.29
Down syndrome, all ages (include age unknown)						12.82	13.49
<20						9.45	10.53
20-24						6.99	7.10
25-29						9.55	10.22
30-34						18.43	15.58
35-39						30.60	39.09
40-44						110.91	127.86
45+						909.09	444.44
unknown						---	---

nr = not reported
* data include less than 5 years

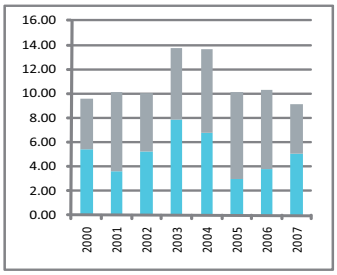
Ukraine: OMNI-Net

'Time trends 2000-2007 (Birth prevalence rates per 10,000)

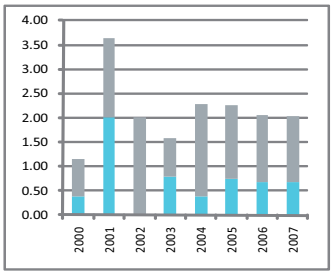
Anencephaly



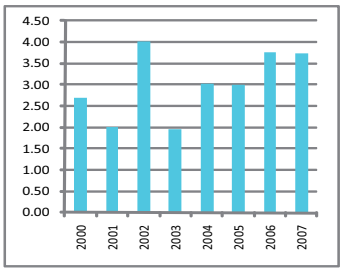
Spina Bifida



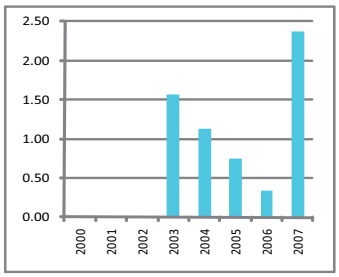
Encephalocele



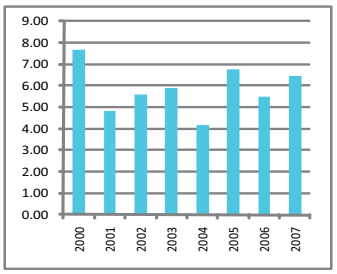
Microcephaly



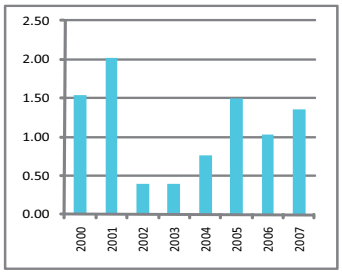
Holoprosencephaly



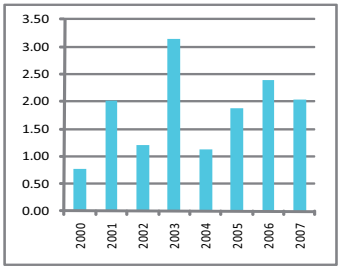
Hydrocephaly



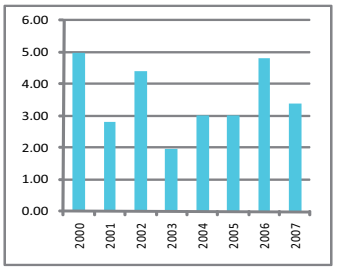
Microphthalmos



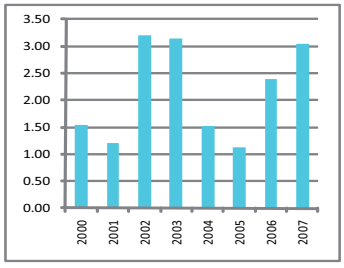
Microtia



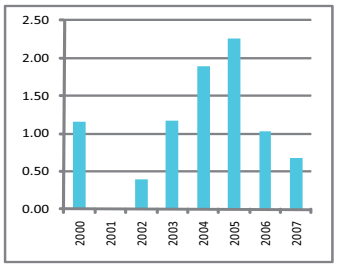
Transposition of great vessels



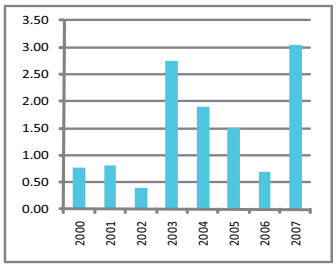
Tetralogy of Fallot



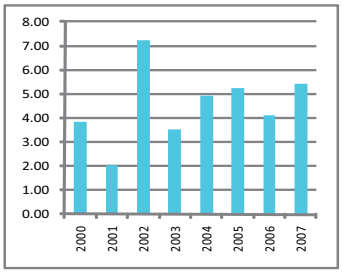
Hypoplastic left heart syndrome



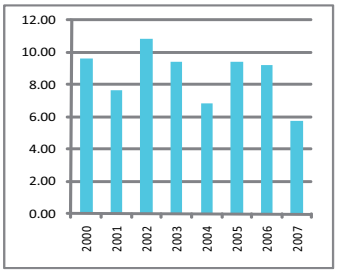
Coarctation of aorta



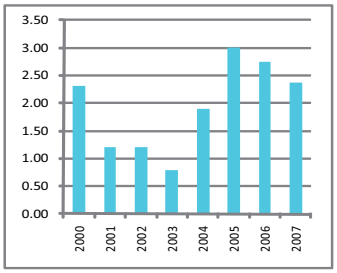
Cleft palate without cleft lip



Cleft lip with or without cleft palate



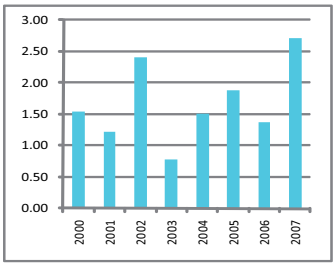
Oesophageal atresia/stenosis with or without fistula



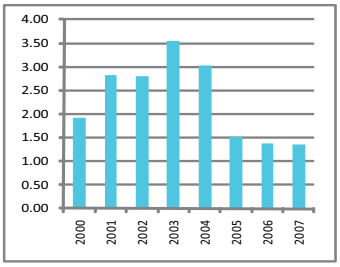
Note: L+S rates, ToP rates

Ukraine: OMNI-Net

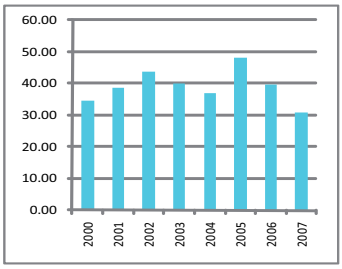
Small intestine atresia/stenosis



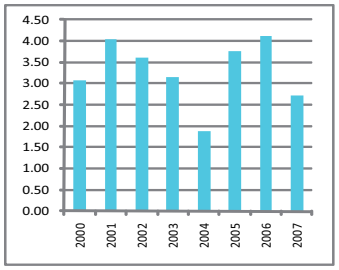
Anorectal atresia/stenosis



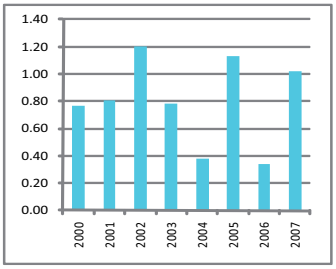
Undescended testis



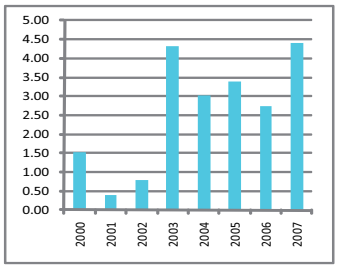
Hypospadias



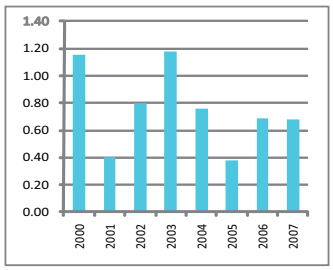
Renal agenesis



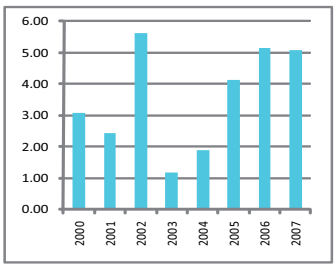
Cystic kidney



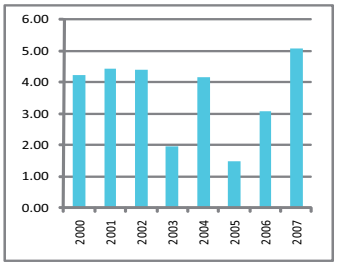
Bladder exstrophy



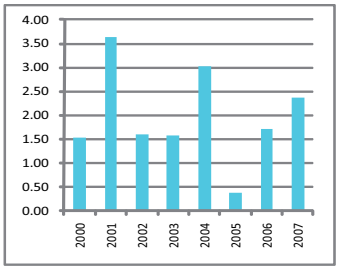
Polydactyly, preaxial



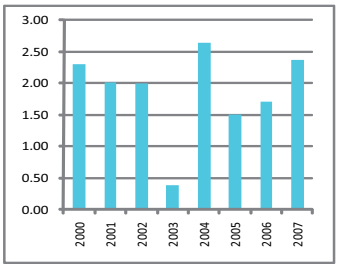
Limb reduction defects



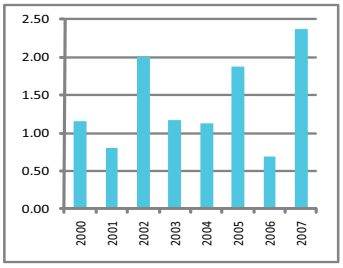
Limb reduction defects - transverse



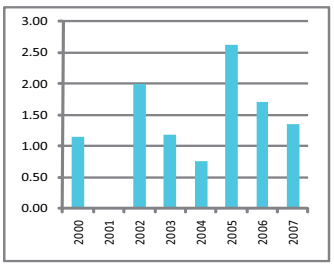
Diaphragmatic hernia



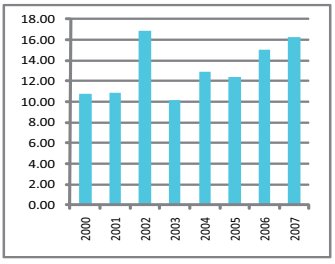
Omphalocele



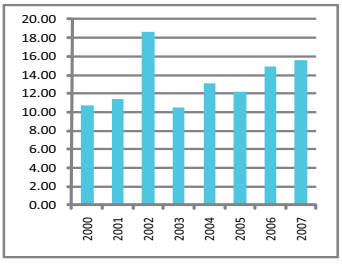
Gastroschisis



Down Syndrome



Down Syndrome standardized total rate



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.

Addresses and Staff:
Dr DianaWellesley
Head Of Prenatal Genetics
Wessex Clinical Genetics Service
Princess Anne Hospital, Southampton SO16 5YA
Phone: +442380 796167
Fax: +442380 794346
E-mail: dgw@soton.ac.uk

Lysa Styles
Specialist Midwife in Fetal Medicine
E-mail: lysa.styles@suht.swest.nhs.uk

UNITED KINGDOM - WESSEX: WANDA, 2007

Live births (LB)	28,893
Stillbirths (SB)	110
Total births	29,003
Number of terminations of pregnancy (ToP) for birth defects	201

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	0	18	6.21
Spina bifida	3	1	6	3.45
Encephalocele	0	0	6	2.07
Microcephaly	0	0	3	1.03
Holoprosencephaly	0	1	2	1.03
Hydrocephaly	7	0	6	4.48
Anophthalmos	nr	nr	nr	nr
Microphthalmos	nr	nr	nr	nr
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	7	0	2	3.10
Tetralogy of Fallot	11	0	0	3.79
Hypoplastic left heart syndrome	7	1	8	5.52
Coarctation of aorta	10	0	0	3.45
Choanal atresia, bilateral	1	0	0	0.34
Cleft palate without cleft lip	25	1	3	10.00
Cleft lip with or without cleft palate	41	1	3	15.52
Oesophageal atresia/stenosis with or without fistula	4	0	0	1.38
Small intestine atresia/stenosis	11	0	0	3.79
Anorectal atresia/stenosis	4	0	2	2.07
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	18	0	0	6.21
Epispadias	nr	nr	nr	nr
Indeterminate sex	3	1	0	1.38
Renal agenesis	3	0	5	2.76
Cystic kidney	18	2	7	9.31
Bladder exstrophy	1	0	0	0.34
Polydactyly, preaxial	4	0	0	1.38
Total Limb reduction defects (include unspecified)	3	0	6	3.10
Transverse	nr	nr	nr	nr
Preaxial	nr	nr	nr	nr
Postaxial	nr	nr	nr	nr
Intercalary	nr	nr	nr	nr
Mixed	nr	nr	nr	nr
Unspecified	nr	nr	nr	nr
Diaphragmatic hernia	10	0	1	3.79
Omphalocele	6	0	8	4.83
Gastroschisis	11	0	3	4.83
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	9	3.79
Trisomy 18	0	2	19	7.24
Down syndrome, all ages (include age unknown)	41	12	48	20.36
<20	0	0	0	9.36
20-24	3	2	0	8.41
25-29	7	4	5	16.65
30-34	12	4	14	18.45
35-39	8	0	19	52.04
40-44	6	1	5	164.52
45+	1	0	1	338.35
unknown	0	0	1	---

nr = not reported

USA-Atlanta: MACDP

Metropolitan Atlanta Congenital Defects Program

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

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

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

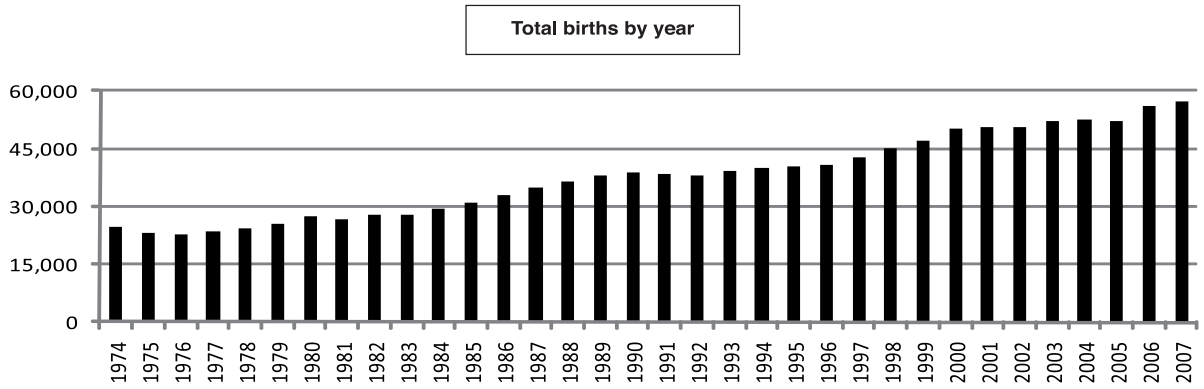
Exposure information:
Exposure information is obtained by interview for mothers of reported malformed infants who participate in various research projects.

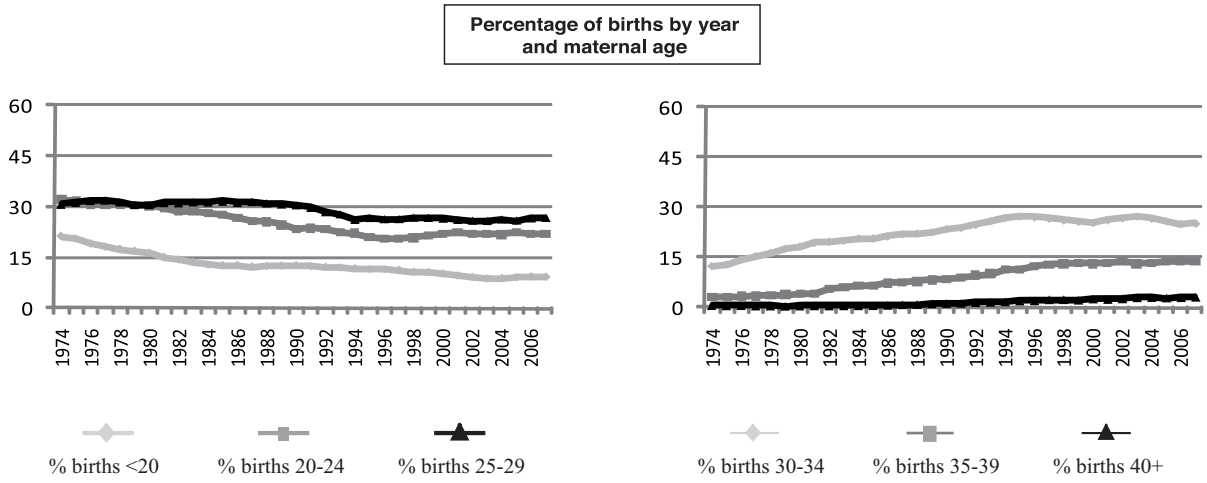
Background information:
Number of live births and demographic information on the five counties are obtained from vital statistics.

Addresses and Staff:
Adolfo Correa MD, PhD
Metropolitan Atlanta Congenital Defects Program
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Mailstop E-86
1600 Clifton Road
Atlanta, GA 30333 USA
Phone: 1-404-4983811
Fax: 1-404-4983040
E-mail: ACorrea@cdc.gov

Csaba Siffel, MD, PhD
E-mail: csiffel@cdc.gov

USA-Atlanta: MACDP





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	25	67.6	Cystic kidney	4	4.6
Spina bifida	21	29.6	Limb reduction defects	4	5.9
Encephalocele	3	17.6	Diaphragmatic hernia	3	7.1
Holoprosencephaly	5	18.5	Omphalocele	5	13.5
Hydrocephaly	11	10.3	Gastroschisis	3	4.2
Hypoplastic left heart syndrome	3	9.4	Trisomy 13	8	38.1
Cleft palate without cleft lip	0	0.0	Trisomy 18	28	47.5
Cleft lip with or without cleft palate	8	5.4	Down syndrome	44	17.0
Renal agenesis	2	12.5			

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

USA-Atlanta: MACDP, 2007

Live births (LB)	56,634
Stillbirths (SB)	566 (*)
Total births	57,200
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	2	8	2.10
Spina bifida	13	4	6	4.02
Encephalocele	6	1	1	1.40
Microcephaly	16	0	0	2.80
Holoprosencephaly	7	1	1	1.57
Hydrocephaly	29	4	3	6.29
Anophthalmos	2	0	0	0.35
Microphthalmos	7	0	0	1.22
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	2	0	0	0.35
Microtia	6	0	0	1.05
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	26	1	1	4.90
Tetralogy of Fallot	16	2	0	3.15
Hypoplastic left heart syndrome	10	1	1	2.10
Coarctation of aorta	28	0	0	4.90
Choanal atresia, bilateral	3	0	0	0.52
Cleft palate without cleft lip	20	0	0	3.50
Cleft lip with or without cleft palate	43	4	2	8.57
Oesophageal atresia/stenosis with or without fistula	9	1	1	1.92
Small intestine atresia/stenosis	7	0	0	1.22
Anorectal atresia/stenosis	23	1	3	4.72
Undescended testis (36 weeks of gestation or later)	25	0	0	4.37
Hypospadias	26	0	0	4.55
Epispadias	2	0	0	0.35
Indeterminate sex	4	2	3	1.57
Renal agenesis	6	0	1	1.22
Cystic kidney	19	1	2	3.85
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	9	0	1	1.75
Total Limb reduction defects (include unspecified)	24	2	1	4.72
Transverse	13	2	0	2.62
Preaxial	1	0	0	0.17
Postaxial	3	0	0	0.52
Intercalary	0	0	1	0.17
Mixed	7	0	0	1.22
Unspecified	0	0	0	0.00
Diaphragmatic hernia	9	0	1	1.75
Omphalocele	13	1	2	2.80
Gastroschisis	30	4	0	5.94
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	2	0	0	0.35
Trisomy 13	1	2	1	0.70
Trisomy 18	8	4	11	4.02
Down syndrome, all ages (include age unknown)	72	3	11	15.03
<20	3	1	0	7.64
20-24	8	0	0	6.40
25-29	14	0	1	9.81
30-34	9	1	2	8.32
35-39	25	0	6	38.95
40-44	12	1	2	89.93
45+	1	0	0	91.74
unknown	0	0	0	---

(*) Total stillbirths are estimated as 1% of total births
nr = not reported

USA-Atlanta: MACDP, Previous years rates 1974 - 2007

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

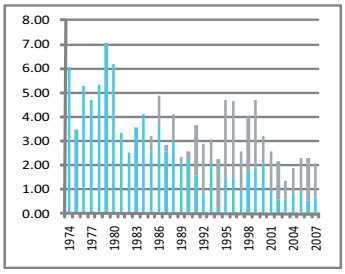
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births	**93,985**	**132,000**	**155,966**	**189,968**	**202,987**	**243,256**	**270,016**
Anencephaly	4.89	4.85	3.72	3.11	3.45	3.29	2.00
Spina bifida	7.77	5.98	6.73	4.79	5.22	3.58	4.00
Encephalocele	1.60	2.73	2.18	1.37	1.77	1.44	1.11
Microcephaly	4.89	5.53	6.41	5.16	6.75	7.81	4.93
Holoprosencephaly	0.21	0.76	1.22	1.37	1.18	0.82	1.26
Hydrocephaly	9.47	10.38	8.01	5.53	6.45	8.14	6.22
Anophthalmos	0.43	0.61	0.64	0.74	0.54	0.25	0.48
Microphthalmos	3.72	3.79	3.85	2.84	3.10	2.71	1.26
Unspecified Anophthalmos / Microphthalmos	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Anotia	0.32	0.08	0.13	0.21	0.20	0.25	0.19
Microtia	1.60	1.14	1.47	1.47	1.28	1.36	1.26
Unspecified Anotia / Microtia	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Transposition of great vessels	4.26	5.45	5.71	4.90	5.27	5.63	4.52
Tetralogy of Fallot	2.45	3.71	3.78	4.16	4.19	4.36	3.74
Hypoplastic left heart syndrome	2.34	2.65	2.31	2.90	2.96	2.88	2.00
Coarctation of aorta	3.94	3.86	4.49	4.90	4.34	6.04	4.96
Choanal atresia, bilateral	0.53	0.08	0.38	0.26	0.44	0.41	0.41
Cleft palate without cleft lip	7.66	5.00	5.13	5.37	4.48	6.74	4.67
Cleft lip with or without cleft palate	11.17	11.52	10.07	9.53	9.06	8.72	9.11
Oesophageal atresia / stenosis with or without fistula	2.55	2.58	2.31	1.90	2.61	2.06	1.81
Small intestine atresia / stenosis	1.38	1.67	1.60	1.84	1.72	1.85	1.85
Anorectal atresia / stenosis	4.89	3.79	4.36	3.26	3.84	3.58	3.15
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr	nr	20.31	10.55
Hypospadias	1.38	0.68	4.30	4.63	5.62	9.87	5.96
Epispadias	1.06	0.98	0.77	0.53	0.54	0.29	0.63
Indeterminate sex	1.81	2.65	0.96	1.42	1.03	1.85	1.26
Renal agenesis	1.81	1.97	1.60	1.37	1.43	0.99	0.93
Cystic kidney	2.45	2.20	4.10	4.42	5.76	6.33	5.48
Bladder exstrophy	0.53	0.38	0.13	0.21	0.25	0.21	0.04
Polydactyly, preaxial	1.49	2.35	2.12	2.90	3.10	2.38	2.15
‘Total Limb reduction defects (include unspecified)	6.60	4.92	4.36	4.84	6.11	6.33	3.85
Transverse	4.26	2.95	2.89	3.37	3.65	3.37	2.04
Preaxial	1.17	0.91	0.51	0.74	1.08	1.40	0.48
Postaxial	0.21	0.30	0.19	0.26	0.30	0.25	0.37
Intercalary	0.43	0.38	0.38	0.16	0.25	0.21	0.22
Mixed	0.00	0.30	0.32	0.21	0.54	0.86	0.63
Unspecified	0.53	0.08	0.06	0.11	0.30	0.21	0.11
Diaphragmatic hernia	3.30	2.05	2.31	2.90	2.07	2.55	2.67
Omphalocele	3.83	3.86	2.89	2.58	2.71	2.30	1.93
Gastroschisis	1.17	2.12	1.67	3.16	2.02	2.55	3.89
Unspecified Omphalocele / Gastroschisis	0.00	0.00	0.00	0.05	0.00	0.00	0.00
Prune belly sequence	0.64	0.76	0.38	0.32	0.20	0.53	0.41
Trisomy 13	0.96	1.06	1.73	1.42	1.63	1.97	1.44
Trisomy 18	0.53	1.29	2.18	2.16	3.50	4.77	4.11
Down syndrome, all ages (include age unknown)	8.83	10.53	9.75	10.74	17.09	17.43	16.52
<20	nr	8.83	6.04	5.97	9.83	7.01	8.23
20-24	nr	6.60	7.52	7.65	8.56	7.18	6.74
25-29	nr	9.82	5.91	6.81	8.50	8.88	7.19
30-34	nr	15.27	14.03	12.57	14.11	13.69	13.22
35-39	nr	32.03	19.87	21.25	43.21	48.05	40.14
40-44	nr	94.79	56.98	60.63	125.36	108.16	117.34
45+	nr	0.00	0.00	175.44	277.78	252.71	91.95
unknown	---	---	---	---	---	---	---

nr = not reported

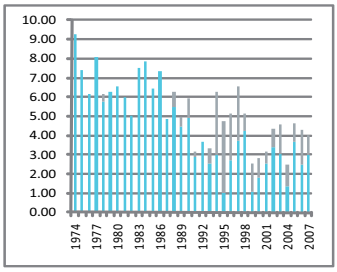
USA-Atlanta: MACDP

'Time trends 1974-2007 (Birth prevalence rates per 10,000)

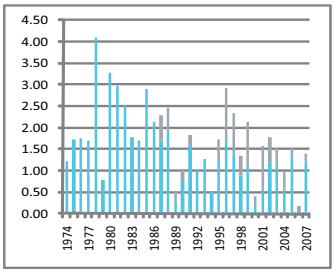
Anencephaly



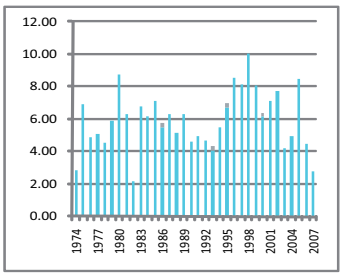
Spina Bifida



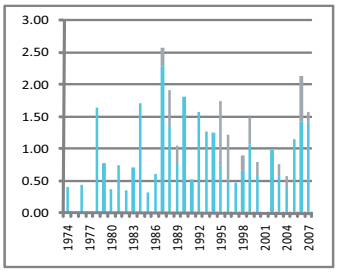
Encephalocele



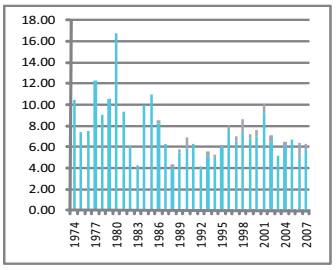
Microcephaly



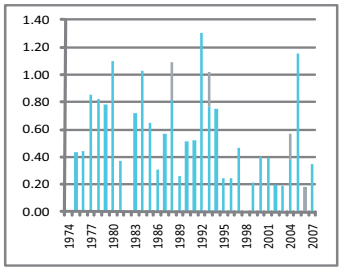
Holoprosencephaly



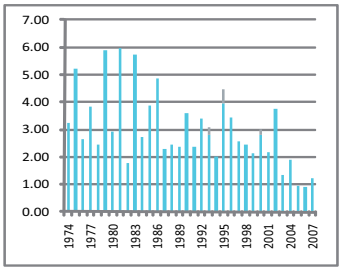
Hydrocephaly



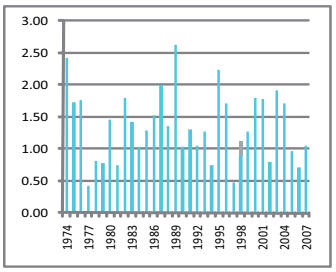
Anophthalmos



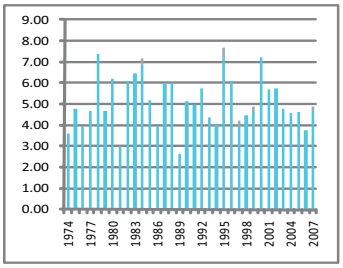
Microphthalmos



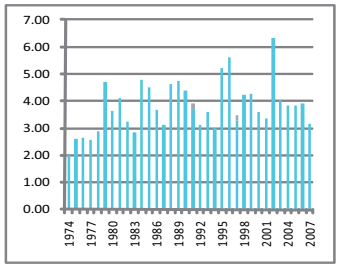
Microtia



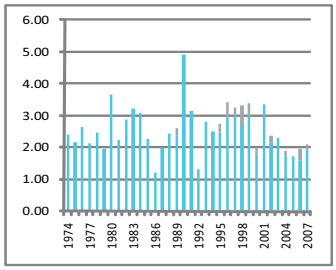
Transposition of great vessels



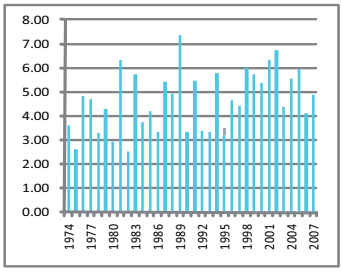
Tetralogy of Fallot



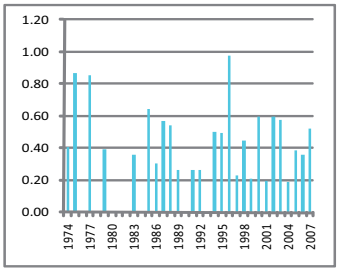
Hypoplastic left heart syndrome



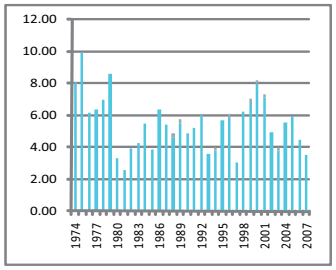
Coarctation of aorta



Choanal atresia, bilateral



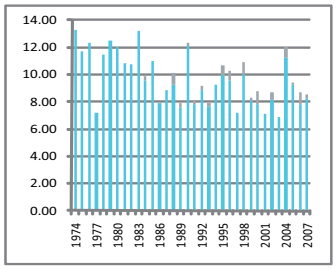
Cleft palate without cleft lip



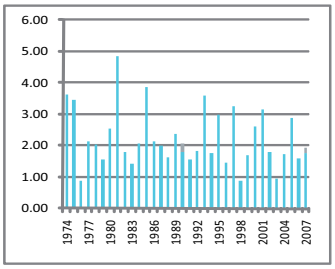
Note: L+S rates, ToP rates

USA-Atlanta: MACDP

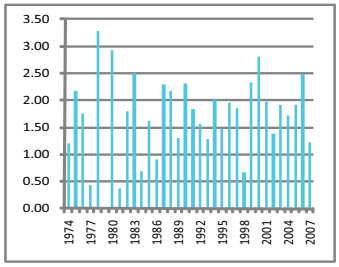
Cleft lip with or without cleft palate



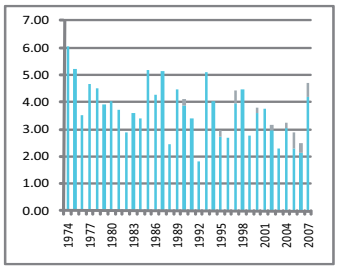
Oesophageal atresia/stenosis with or without fistula



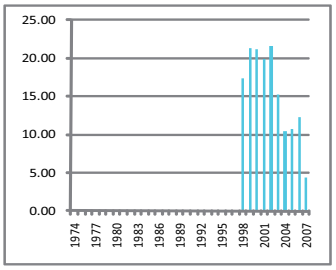
Small intestine atresia/stenosis



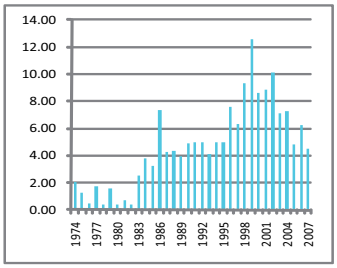
Anorectal atresia/stenosis



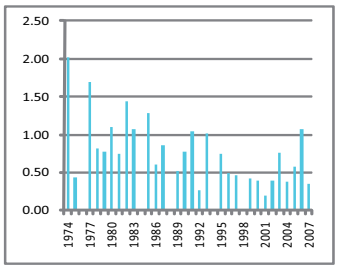
Undescended testis



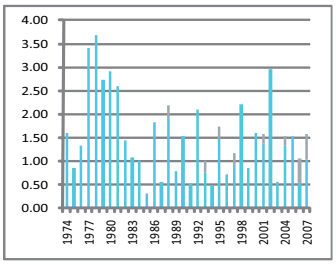
Hypospadias



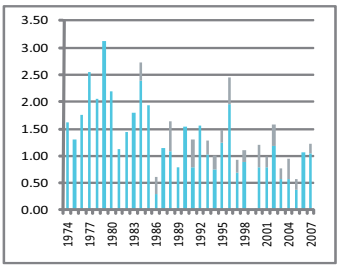
Epispadias



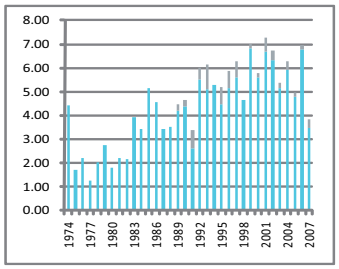
Indeterminate sex



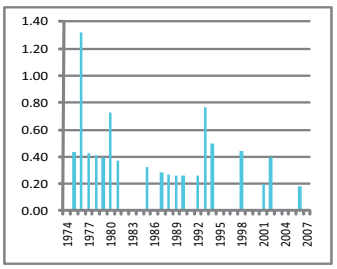
Renal agenesis



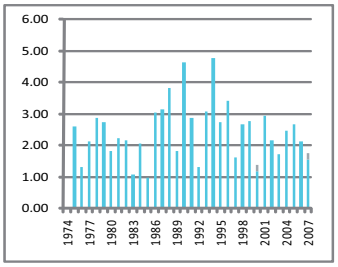
Cystic kidney



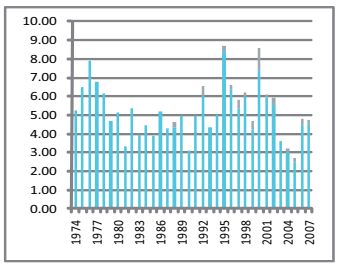
Bladder exstrophy



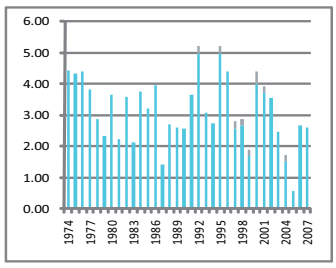
Polydactyly, preaxial



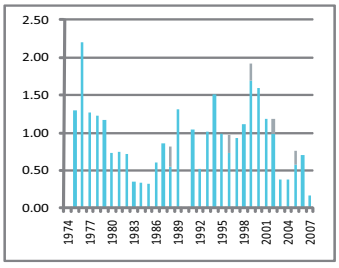
Limb reduction defects



Limb reduction defects - transverse



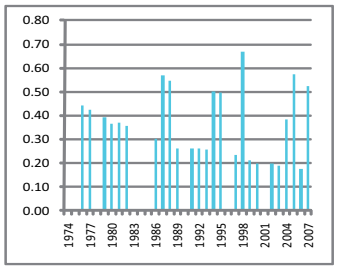
Limb reduction defects - preaxial



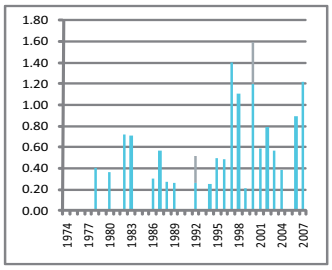
Note: L+S rates, ToP rates

USA-Atlanta: MACDP

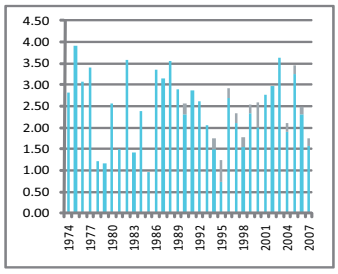
Limb reduction defects - postaxial



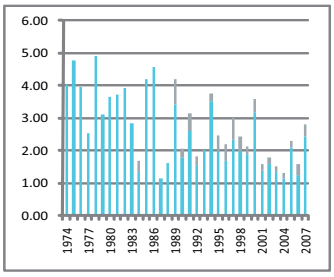
Limb reduction defects - mixed



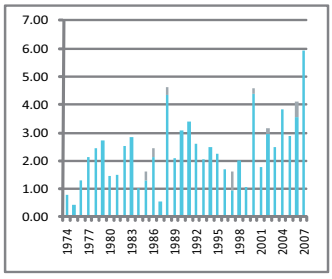
Diaphragmatic hernia



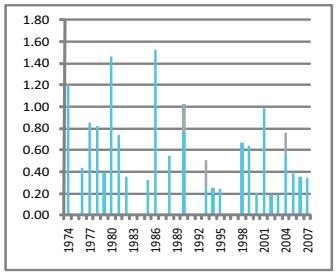
Omphalocele



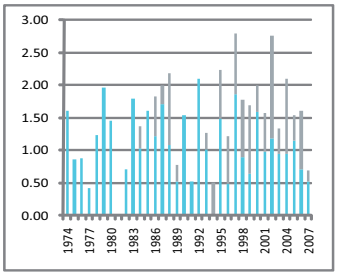
Gastroschisis



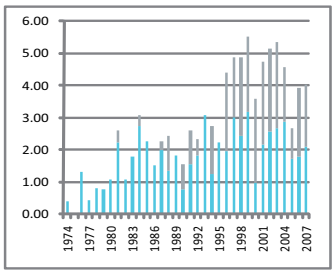
Prune belly sequence



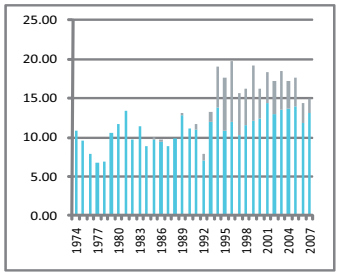
Trisomy 13



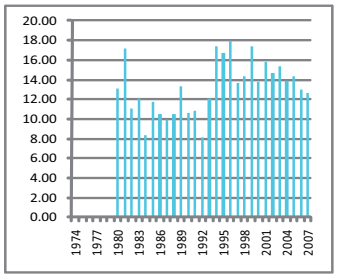
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

USA-Texas: BDES

Texas Birth Defects Epidemiology and Surveillance Branch

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

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

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

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

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

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

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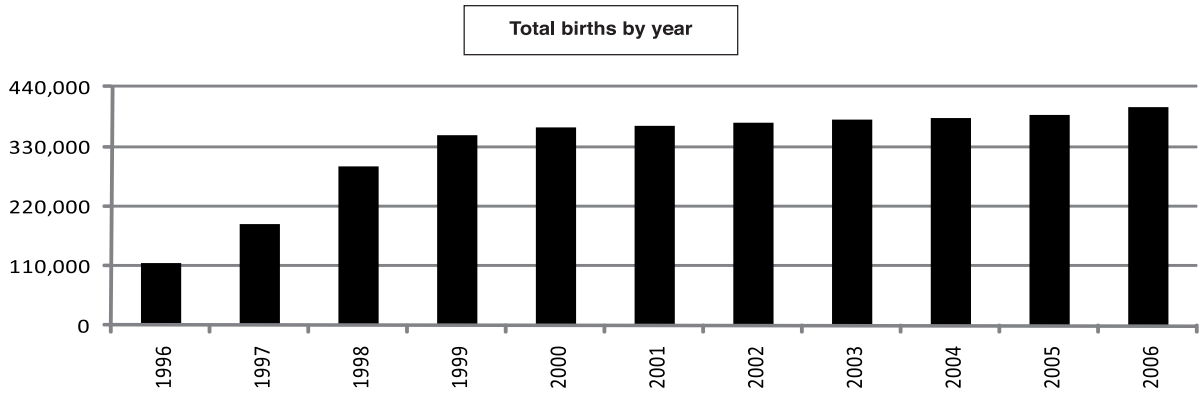
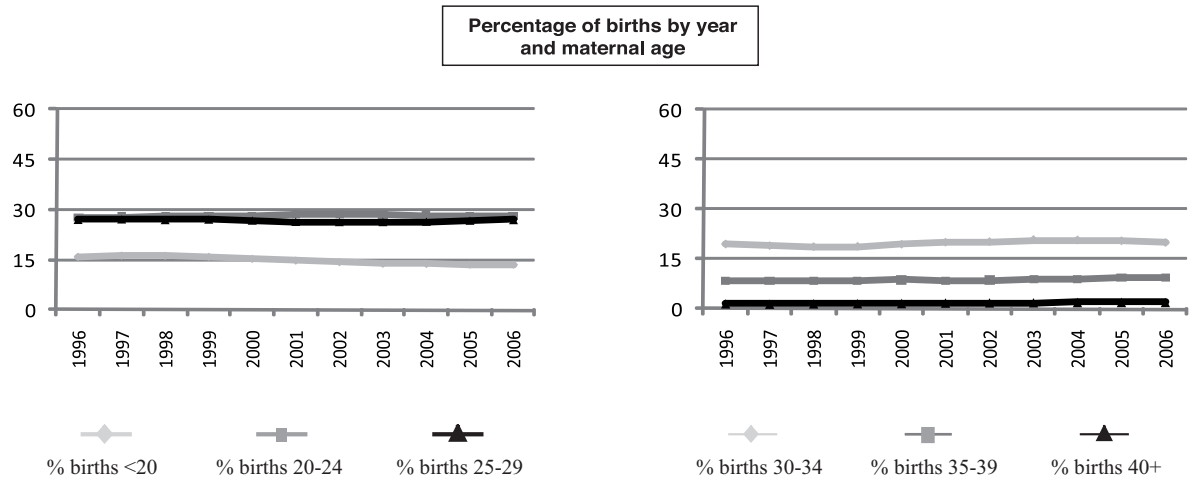
USA-Texas: BDES





Terminations of Pregnancy (ToPs) in selected malformations (2004-2006)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	90	34.0	Cystic kidney	15	2.3
Spina bifida	23	5.1	Limb reduction defects	19	3.0
Encephalocele	14	15.1	Diaphragmatic hernia	3	0.9
Holoprosencephaly	13	9.8	Omphalocele	19	7.9
Hydrocephaly	11	1.6	Gastroschisis	13	2.2
Hypoplastic left heart syndrome	0	0.0	Trisomy 13	21	17.1
Cleft palate without cleft lip	4	0.6	Trisomy 18	67	22.6
Cleft lip with or without cleft palate	32	2.4	Down syndrome	49	3.1
Renal agenesis	19	8.6			

Total ToPs with births defects = 543 (Ratio ToPs/Births: 0.46 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Texas: BDES, 2006

Live births (LB)	399,603
Stillbirths (SB)	2,383
Total births	401,986
Number of terminations of pregnancy (ToP) for birth defects	197

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	25	33	32	2.24
Spina bifida	117	10	7	3.33
Encephalocele	29	4	5	0.95
Microcephaly	397	1	0	9.90
Holoprosencephaly	40	4	4	1.19
Hydrocephaly	226	9	6	6.00
Anophthalmos	10	4	1	0.37
Microphthalmos	117	2	0	2.96
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	15	1	0	0.40
Microtia	120	0	0	2.99
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	210	0	0	5.22
Tetralogy of Fallot	150	0	0	3.73
Hypoplastic left heart syndrome	86	0	0	2.14
Coarctation of aorta	220	3	0	5.55
Choanal atresia, bilateral	57	1	0	1.44
Cleft palate without cleft lip	204	5	0	5.20
Cleft lip with or without cleft palate	416	19	8	11.02
Oesophageal atresia/stenosis with or without fistula	79	0	0	1.97
Small intestine atresia/stenosis	77	1	0	1.94
Anorectal atresia/stenosis	193	5	3	5.00
Undescended testis (36 weeks of gestation or later)	456	1	0	11.37
Hypospadias	592	0	1	14.75
Epispadias	41	0	0	1.02
Indeterminate sex	18	6	2	0.65
Renal agenesis	68	8	7	2.06
Cystic kidney	214	4	4	5.52
Bladder exstrophy	4	2	0	0.15
Polydactyly, preaxial	141	0	0	3.51
Total Limb reduction defects (include unspecified)	198	12	7	5.40
Transverse	101	7	5	2.81
Preaxial	48	2	1	1.27
Postaxial	9	0	0	0.22
Intercalary	5	0	1	0.15
Mixed	29	0	0	0.72
Unspecified	6	3	0	0.22
Diaphragmatic hernia	111	6	1	2.94
Omphalocele	63	14	8	2.11
Gastroschisis	189	12	4	5.10
Unspecified Omphalocele/Gastroschisis	13	5	4	0.55
Prune belly sequence	7	1	1	0.22
Trisomy 13	29	5	8	1.04
Trisomy 18	61	19	25	2.61
Down syndrome, all ages (include age unknown)	530	13	19	13.98
<20	50	1	0	9.38
20-24	75	2	1	6.87
25-29	82	4	2	8.13
30-34	100	3	3	13.26
35-39	139	3	6	39.01
40-44	77	0	7	112.69
45+	7	0	0	152.17
unknown	0	0	0	---

USA-Texas: BDES, Previous years rates 1996 - 2006

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

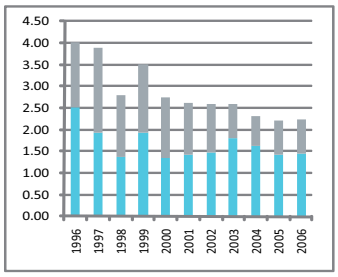
	1974-1981	1982-1986	1987-1991	1992-1996*	1997-2001	2002-2006
Total births				**114,759**	**1,565,355**	**1,927,845**
Anencephaly				4.01	3.03	2.39
Spina bifida				5.75	4.00	3.54
Encephalocele				1.57	1.00	0.80
Microcephaly				5.58	6.45	8.85
Holoprosencephaly				1.66	1.30	1.20
Hydrocephaly				6.36	6.97	6.04
Anophthalmos				0.26	0.35	0.35
Microphthalmos				1.92	2.52	2.67
Unspecified Anophthalmos / Microphthalmos				0.00	0.00	0.00
Anotia				0.35	0.22	0.31
Microtia				2.53	2.51	2.77
Unspecified Anotia / Microtia				0.00	0.00	0.00
Transposition of great vessels				4.88	4.94	4.82
Tetralogy of Fallot				2.79	3.12	3.57
Hypoplastic left heart syndrome				2.27	2.05	2.12
Coarctation of aorta				5.23	4.43	5.19
Choanal atresia, bilateral				0.96	1.25	1.12
Cleft palate without cleft lip				5.66	5.85	5.29
Cleft lip with or without cleft palate				10.28	10.86	10.76
Oesophageal atresia / stenosis with or without fistula				2.09	2.12	2.00
Small intestine atresia / stenosis				1.66	1.76	1.69
Anorectal atresia / stenosis				4.01	4.50	5.05
Undescended testis (36 weeks of gestation or later)				5.84	8.37	10.32
Hypospadias				15.77	18.19	15.81
Epispadias				0.70	0.68	0.71
Indeterminate sex				1.48	1.47	0.78
Renal agenesis				1.66	2.11	1.90
Cystic kidney				4.71	4.39	5.18
Bladder exstrophy				0.17	0.20	0.22
Polydactyly, preaxial				2.18	2.97	3.52
‘Total Limb reduction defects (include unspecified)				5.49	5.51	5.29
Transverse				2.35	2.66	2.81
Preaxial				1.39	1.12	1.09
Postaxial				0.35	0.24	0.23
Intercalary				0.17	0.10	0.13
Mixed				1.13	1.20	0.81
Unspecified				0.09	0.20	0.21
Diaphragmatic hernia				2.61	2.63	2.72
Omphalocele				1.83	2.33	2.03
Gastroschisis				3.22	3.95	4.70
Unspecified Omphalocele / Gastroschisis				0.96	0.61	0.57
Prune belly sequence				0.44	0.26	0.30
Trisomy 13				1.05	1.24	1.08
Trisomy 18				3.14	2.27	2.38
Down syndrome, all ages (include age unknown)				12.03	12.54	12.81
<20				6.57	7.34	7.50
20-24				5.35	7.01	6.39
25-29				6.14	7.38	7.09
30-34				12.56	12.20	12.49
35-39				38.41	36.15	36.21
40-44				138.01	118.50	113.22
45+				126.58	167.60	186.82
unknown				---	---	---

* data include less than 5 years

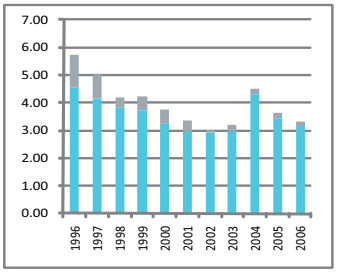
USA-Texas: BDES

'Time trends 1996-2006 (Birth prevalence rates per 10,000)

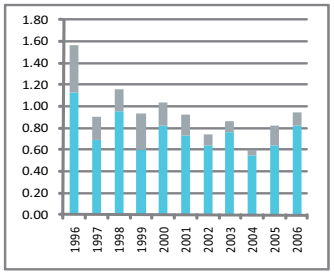
Anencephaly



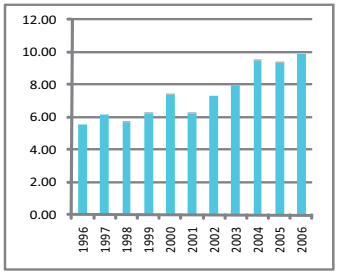
Spina Bifida



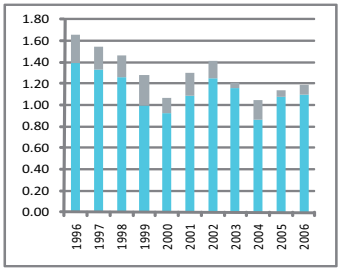
Encephalocele



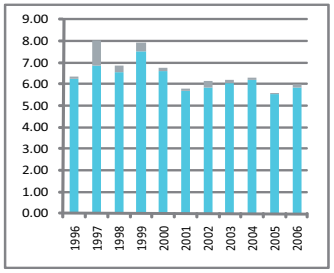
Microcephaly



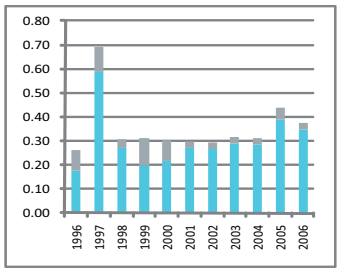
Holoprosencephaly



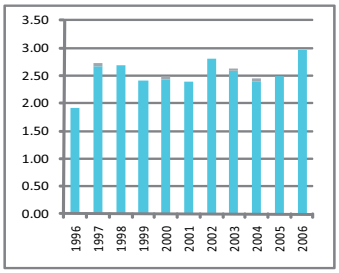
Hydrocephaly



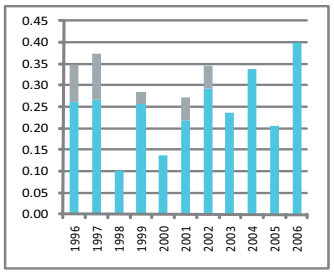
Anophthalmos



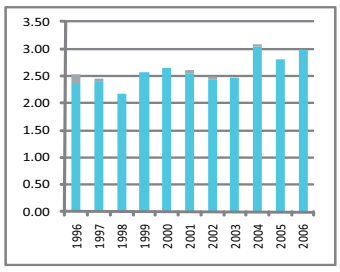
Microphthalmos



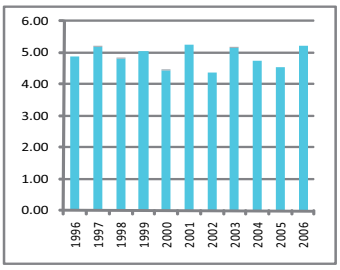
Anotia



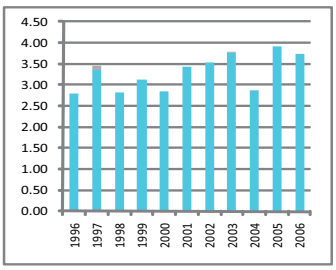
Microtia



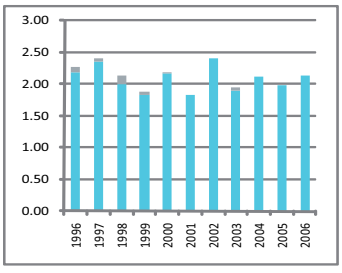
Transposition of great vessels



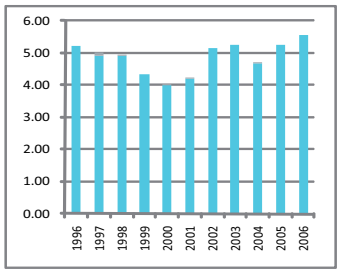
Tetralogy of Fallot



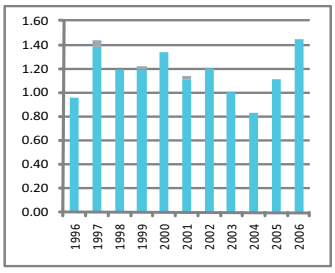
Hypoplastic left heart syndrome



Coarctation of aorta



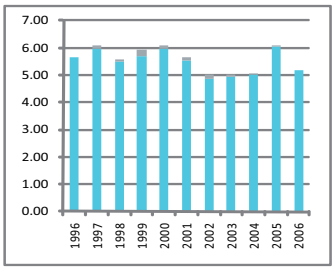
Choanal atresia, bilateral



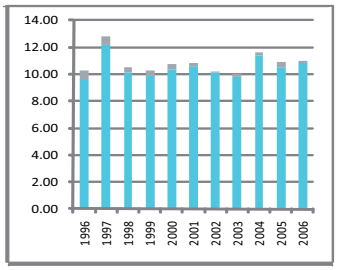
Note: L+S rates, ToP rates

USA-Texas: BDES

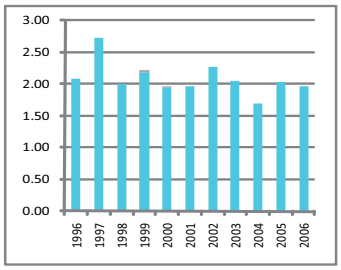
Cleft palate without cleft lip



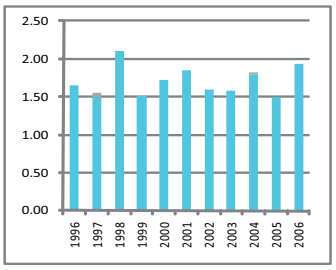
Cleft lip with or without cleft palate



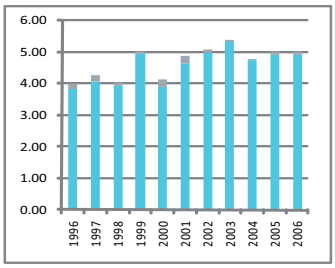
Oesophageal atresia/stenosis with or without fistula



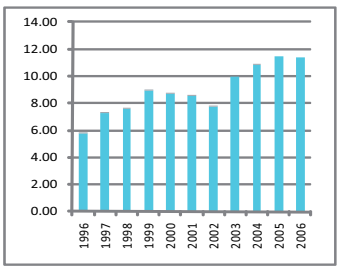
Small intestine atresia/stenosis



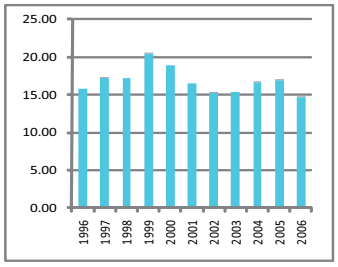
Anorectal atresia/stenosis



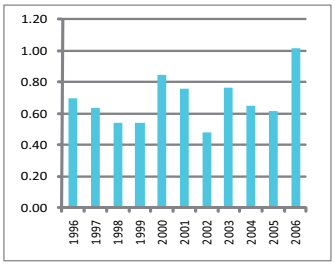
Undescended testis



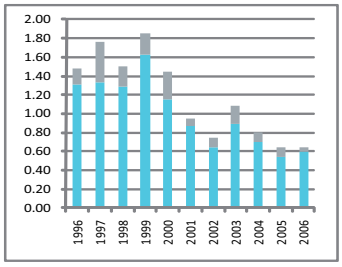
Hypospadias



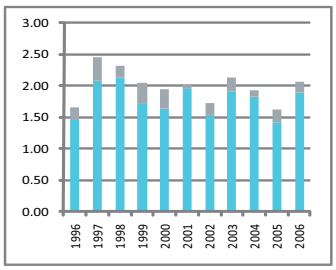
Epispadias



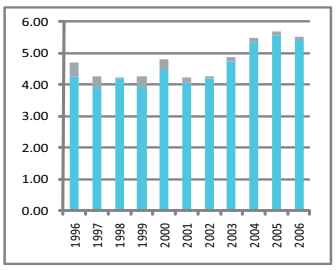
Indeterminate sex



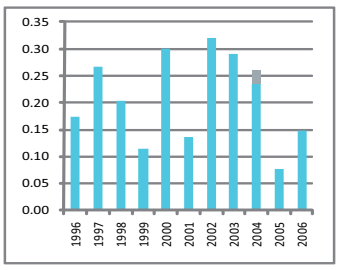
Renal agenesis



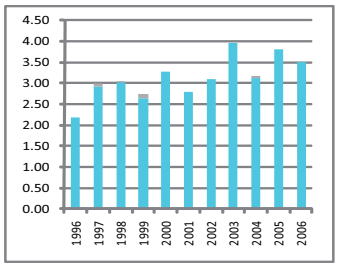
Cystic kidney



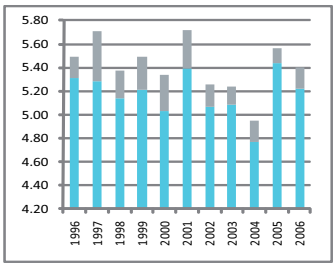
Bladder exstrophy



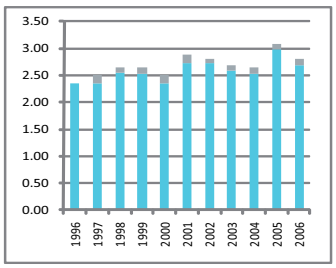
Polydactyly, preaxial



Limb reduction defects



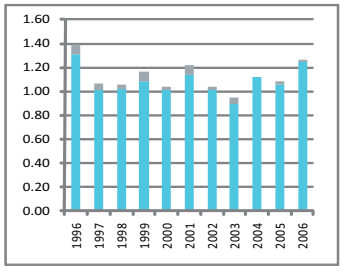
Limb reduction defects - transverse



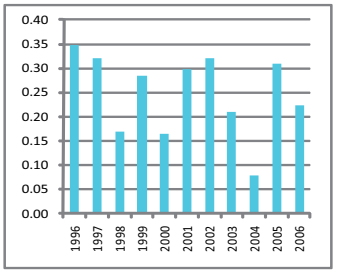
Note: L+S rates, ToP rates

USA-Texas: BDES

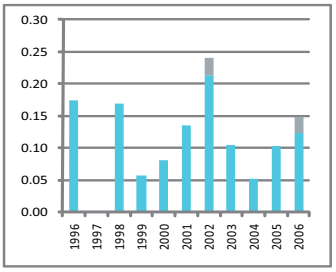
Limb reduction defects - preaxial



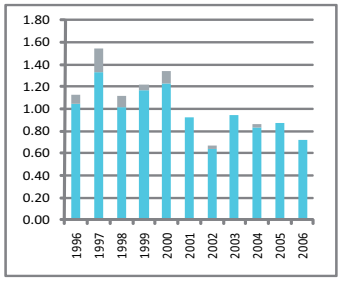
Limb reduction defects - postaxial



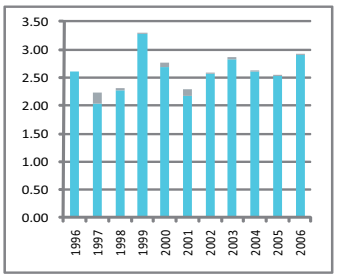
Limb reduction defects - intercalary



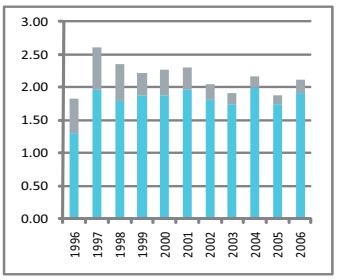
Limb reduction defects - mixed



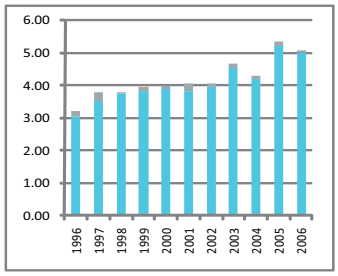
Diaphragmatic hernia



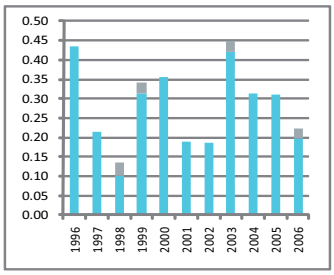
Omphalocele



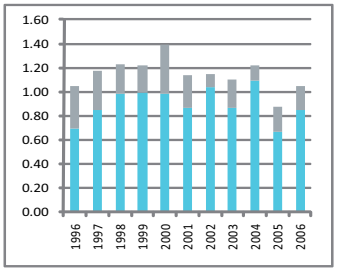
Gastroschisis



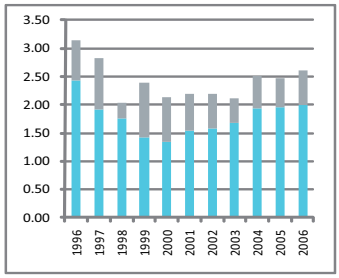
Prune belly sequence



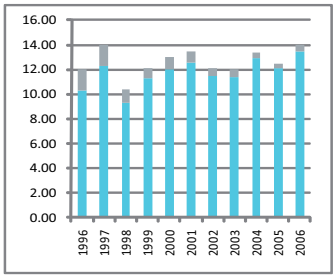
Trisomy 13



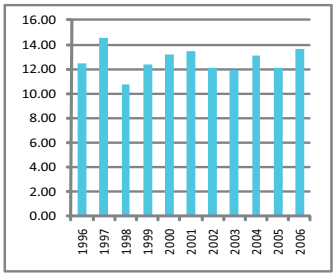
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

USA-Utah: UBDN
Birth Defect 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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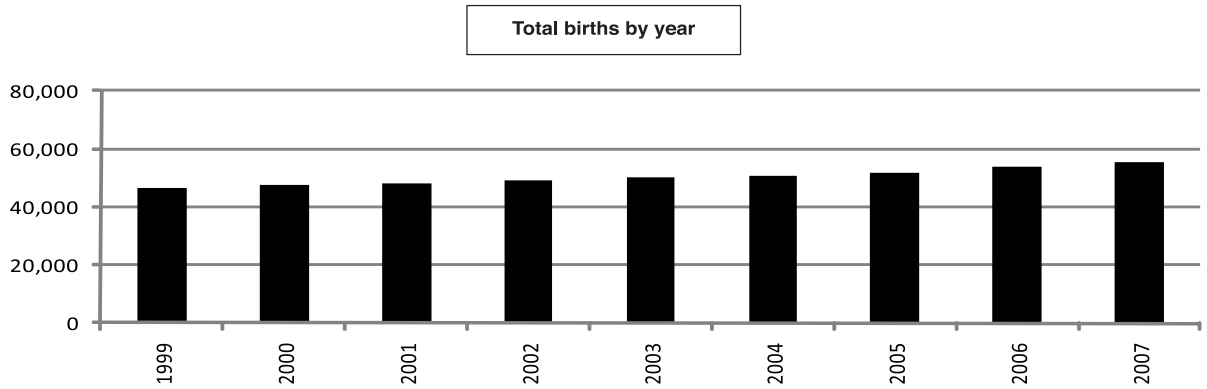
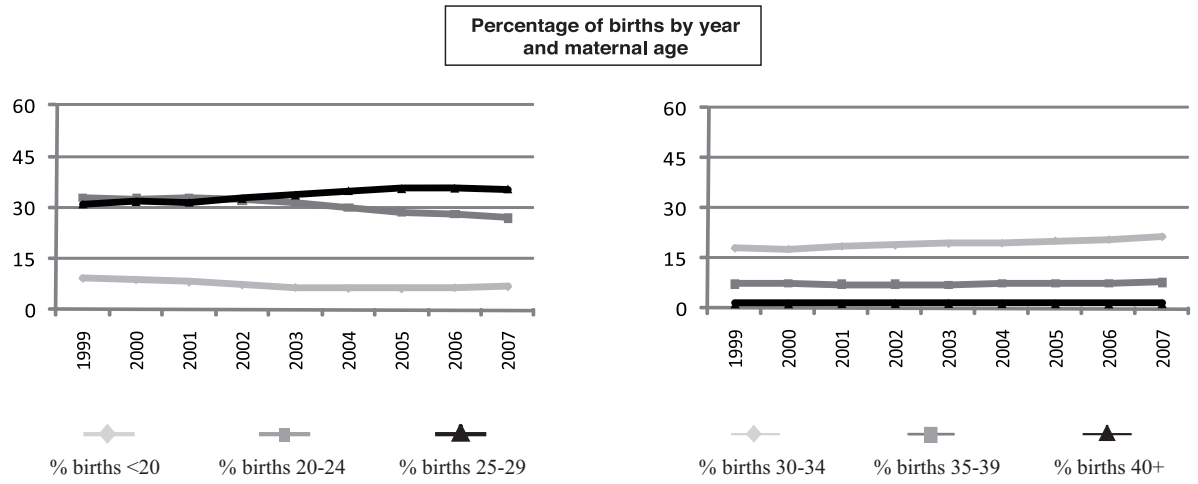
Salt Lake City, Utah 84114-4697 USA
Phone: 801 584 8573
Fax: 801 883 4668
E-mail: mpalmer@utah.gov

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

USA-Utah: UBDN





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	22	52.4	Cystic kidney	8	10.4
Spina bifida	4	5.6	Limb reduction defects	10	9.2
Encephalocele	2	15.4	Diaphragmatic hernia	1	2.0
Holoprosencephaly	10	33.3	Omphalocele	10	28.6
Hydrocephaly	6	8.8	Gastroschisis	1	1.2
Hypoplastic left heart syndrome	2	3.6	Trisomy 13	12	33.3
Cleft palate without cleft lip	3	2.6	Trisomy 18	13	22.8
Cleft lip with or without cleft palate	11	5.5	Down syndrome	18	8.0
Renal agenesis	7	11.7			

Total ToPs with births defects = 112 (Ratio ToPs/Births: 0.70 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

USA-Utah: UBDN, 2007

Live births (LB)	55,063
Stillbirths (SB)	257
Total births	55,320
Number of terminations of pregnancy (ToP) for birth defects	31

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	5	1	6	2.17
Spina bifida	23	1	2	4.70
Encephalocele	2	0	1	0.54
Microcephaly	23	1	1	4.52
Holoprosencephaly	6	1	2	1.63
Hydrocephaly	22	4	0	4.70
Anophthalmos	1	0	0	0.18
Microphthalmos	7	1	0	1.45
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	20	1	0	3.80
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	26	0	0	4.70
Tetralogy of Fallot	13	3	0	2.89
Hypoplastic left heart syndrome	18	1	2	3.80
Coarctation of aorta	47	3	0	9.04
Choanal atresia, bilateral	0	0	0	0.00
Cleft palate without cleft lip	39	2	1	7.59
Cleft lip with or without cleft palate	64	3	1	12.29
Oesophageal atresia/stenosis with or without fistula	20	1	1	3.98
Small intestine atresia/stenosis	10	1	1	2.17
Anorectal atresia/stenosis	19	2	1	3.98
Undescended testis (36 weeks of gestation or later)	nr	nr	nr	nr
Hypospadias	39	0	0	7.05
Epispadias	0	0	0	0.00
Indeterminate sex	nr	nr	nr	nr
Renal agenesis	15	3	2	3.62
Cystic kidney	19	3	1	4.16
Bladder exstrophy	0	0	0	0.00
Polydactyly, preaxial	nr	nr	nr	nr
Total Limb reduction defects (include unspecified)	30	3	0	5.97
Transverse	22	2	0	4.34
Preaxial	3	0	0	0.54
Postaxial	0	0	0	0.00
Intercalary	2	0	0	0.36
Mixed	3	1	0	0.72
Unspecified	0	0	0	0.00
Diaphragmatic hernia	16	1	0	3.07
Omphalocele	4	1	3	1.45
Gastroschisis	26	1	1	5.06
Unspecified Omphalocele/Gastroschisis	0	0	0	0.00
Prune belly sequence	0	0	1	0.18
Trisomy 13	4	4	3	1.99
Trisomy 18	7	6	4	3.07
Down syndrome, all ages (include age unknown)	66	5	6	13.92
<20	4	0	0	10.50
20-24	8	0	0	5.38
25-29	22	2	1	12.73
30-34	12	1	0	10.97
35-39	8	1	2	25.61
40-44	10	1	3	175.66
45+	2	0	0	363.64
unknown	0	0	0	---

nr = not reported

USA-Utah: UBDN, Previous years rates 1999 - 2007

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

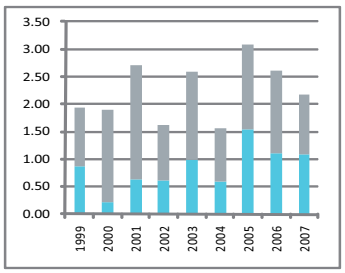
	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002*	2003-2007
Total births						**191,575**	**261,811**
Anencephaly						2.04	2.41
Spina bifida						3.71	4.35
Encephalocele						0.89	0.80
Microcephaly						4.07	5.46
Holoprosencephaly						1.25	1.68
Hydrocephaly						4.02	4.62
Anophthalmos						0.10	0.38
Microphthalmos						1.57	1.41
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.16	0.15
Microtia						2.09	3.02
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						5.59	4.51
Tetralogy of Fallot						4.54	3.70
Hypoplastic left heart syndrome						3.81	3.40
Coarctation of aorta						7.52	8.98
Choanal atresia, bilateral						0.05	0.31
Cleft palate without cleft lip						7.78	7.07
Cleft lip with or without cleft palate						14.56	12.80
Oesophageal atresia / stenosis with or without fistula						2.71	2.75
Small intestine atresia / stenosis						1.15	1.68
Anorectal atresia / stenosis						3.29	3.55
Undescended testis (36 weeks of gestation or later)						nr	nr
Hypospadias						4.38	7.41
Epispadias						0.21	0.11
Indeterminate sex						nr	nr
Renal agenesis						3.55	3.70
Cystic kidney						5.38	5.04
Bladder exstrophy						0.26	0.08
Polydactyly, preaxial						nr	nr
‘Total Limb reduction defects (include unspecified)						5.69	6.53
Transverse						3.13	3.55
Preaxial						1.51	1.34
Postaxial						0.05	0.11
Intercalary						0.05	0.19
Mixed						0.68	1.03
Unspecified						0.21	0.08
Diaphragmatic hernia						3.65	3.09
Omphalocele						2.77	2.37
Gastroschisis						4.23	5.35
Unspecified Omphalocele / Gastroschisis						0.00	0.00
Prune belly sequence						0.16	0.15
Trisomy 13						1.51	1.99
Trisomy 18						3.45	3.44
Down syndrome, all ages (include age unknown)						15.29	14.93
<20						9.94	10.46
20-24						8.18	8.70
25-29						8.36	9.79
30-34						15.34	11.67
35-39						50.80	46.34
40-44						144.67	148.67
45+						500.00	322.58
unknown						---	---

nr = not reported
* data include less than 5 years

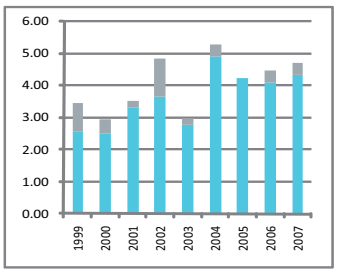
USA-Utah: UBDN

'Time trends 1999-2007 (Birth prevalence rates per 10,000)

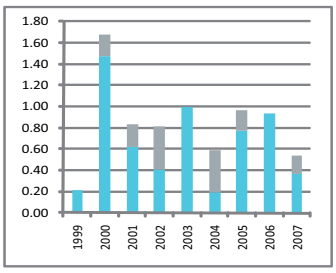
Anencephaly



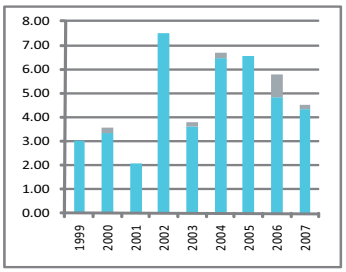
Spina Bifida



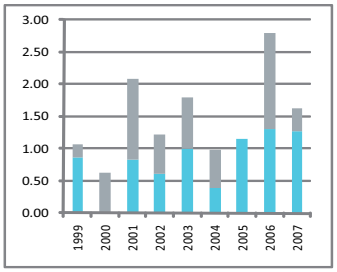
Encephalocele



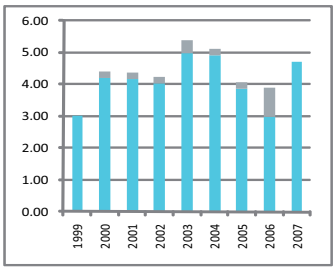
Microcephaly



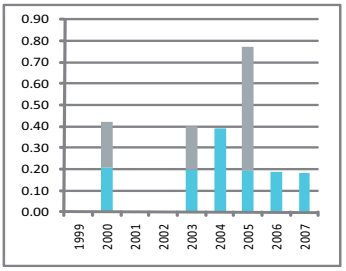
Holoprosencephaly



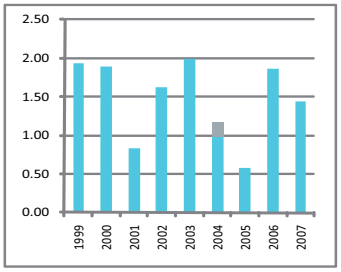
Hydrocephaly



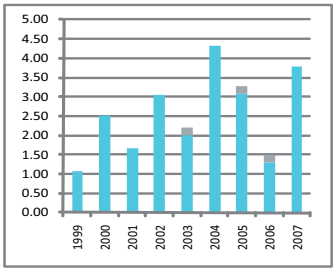
Anophthalmos



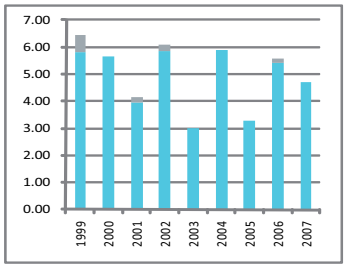
Microphthalmos



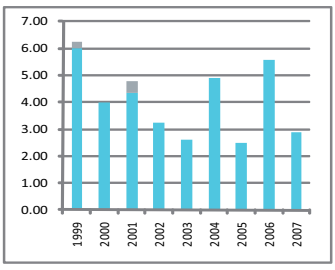
Microtia



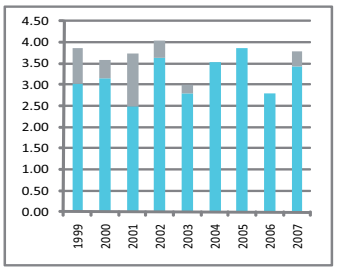
Transposition of great vessels



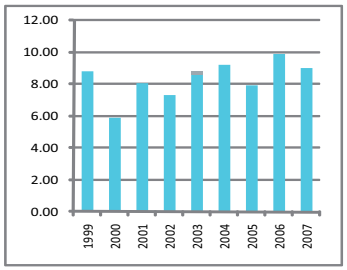
Tetralogy of Fallot



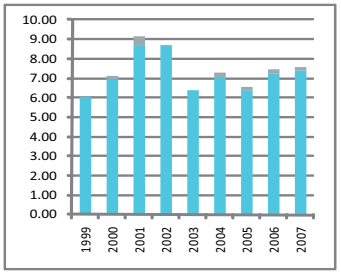
Hypoplastic left heart syndrome



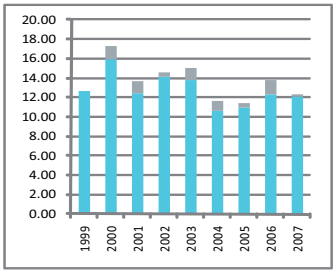
Coarctation of aorta



Cleft palate without cleft lip



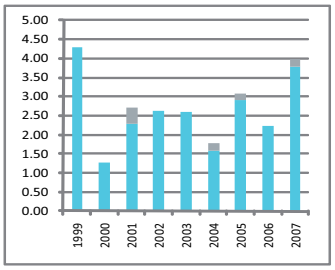
Cleft lip with or without cleft palate



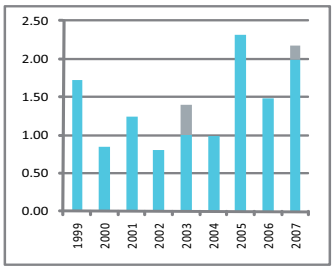
Note: L+S rates, ToP rates

USA-Utah: UBDN

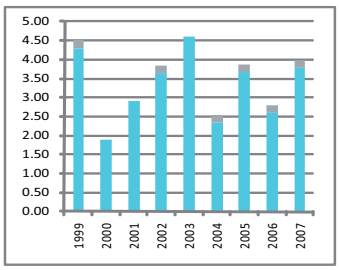
Oesophageal atresia/stenosis with or without fistula



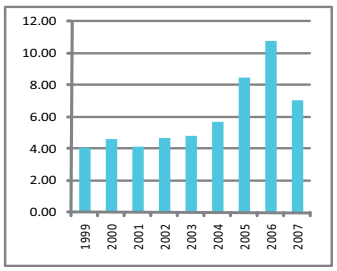
Small intestine atresia/stenosis



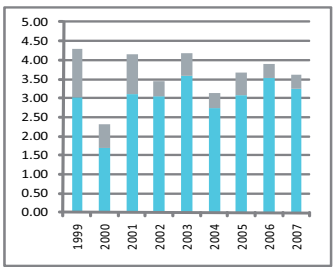
Anorectal atresia/stenosis



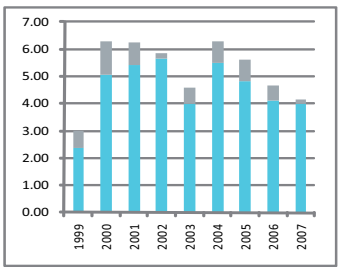
Hypospadias



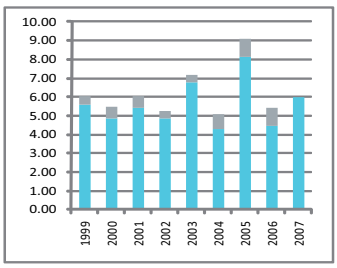
Renal agenesis



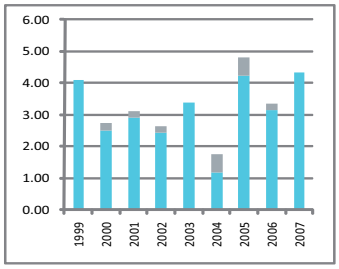
Cystic kidney



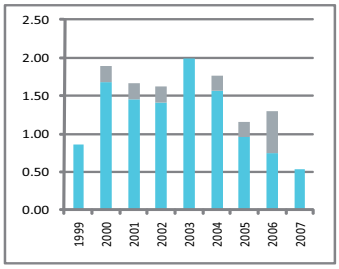
Limb reduction defects



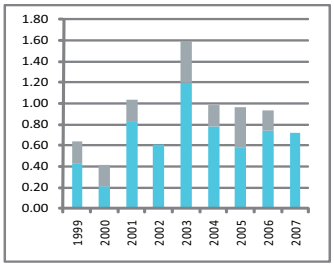
Limb reduction defects - transverse



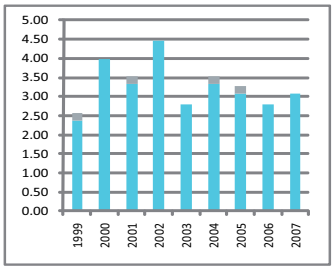
Limb reduction defects - preaxial



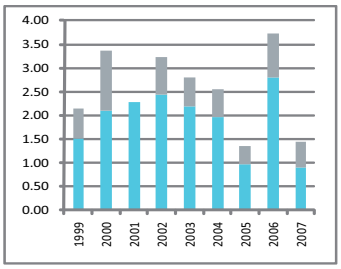
Limb reduction defects - mixed



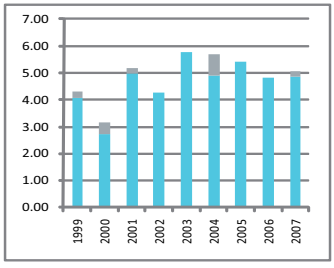
Diaphragmatic hernia



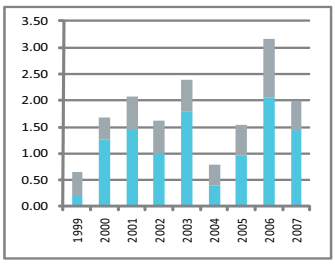
Omphalocele



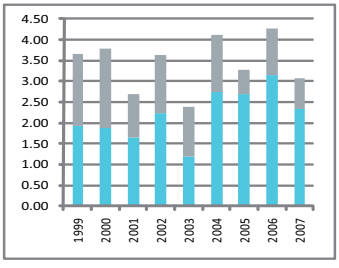
Gastroschisis



Trisomy 13



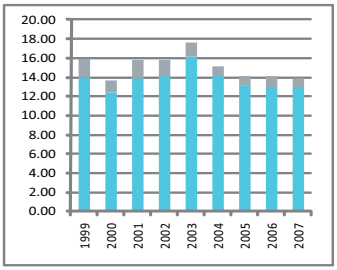
Trisomy 18



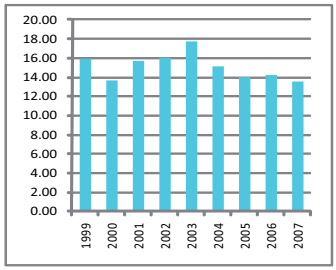
Note: L+S rates, ToP rates

USA-Utah: UBDN

Down Syndrome



Down Syndrome standardized total rate



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.

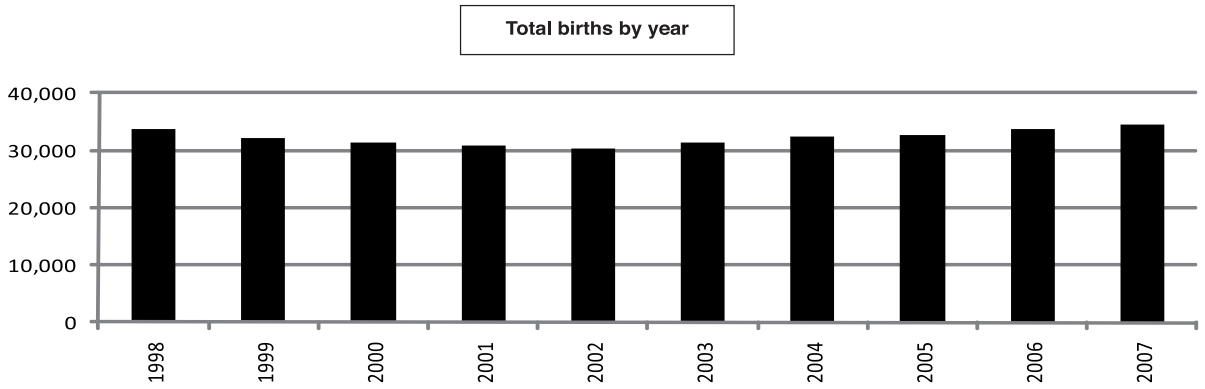
Exposure Data Availability:
xposure information: information on maternal drug use, maternal and paternal diseases and occupations, outcomes of previous pregnancies is available. Folic acid supplementation before and during pregnancy is also collected.

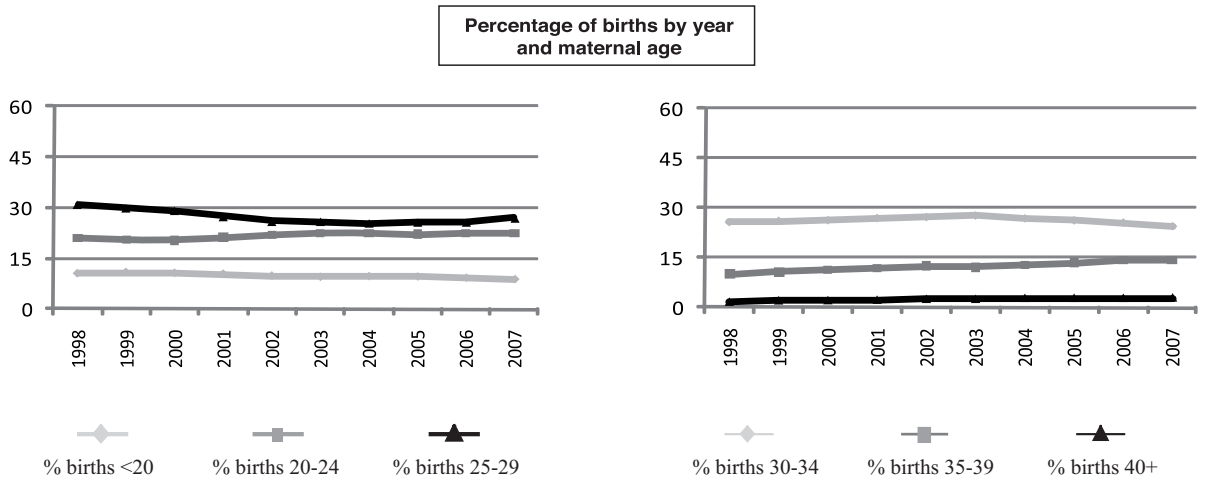
Denominators and Controls Information:
Denominator date is obtained from the Office for National Statistics.

Addresses and Staff:
Margery Morgan, Programme Director
Congenital Anomaly Register and Information Service (CARIS)
Level 3 West Wing,
Singleton Hospital, Sketty Lane
Swansea, Wales, SA2 8QA
Phone: 44-1792-285241
Fax: 44-1792- 285242

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

Wales: CARIS





Terminations of Pregnancy (ToPs) in selected malformations (2005-2007)
(Total cases: isolated + multiples + syndromes)

Birth defects	ToPs	% of ToPs (*)	Birth defects	ToPs	% of ToPs (*)
Anencephaly	45	95.7	Cystic kidney	23	26.1
Spina bifida	57	81.4	Limb reduction defects	24	25.8
Encephalocele	18	81.8	Diaphragmatic hernia	13	30.2
Holoprosencephaly	10	90.9	Omphalocele	26	59.1
Hydrocephaly	44	51.8	Gastroschisis	3	4.7
Hypoplastic left heart syndrome	18	54.5	Trisomy 13	15	83.3
Cleft palate without cleft lip	11	11.2	Trisomy 18	46	70.8
Cleft lip with or without cleft palate	14	12.4	Down syndrome	120	51.3
Renal agenesis	22	88.0			

Total ToPs with births defects = 522 (Ratio ToPs/Births: 5.16 per 1,000)
(*) % of ToPs = ToPs/(ToPs+Births)

Wales: CARIS, 2007

Live births (LB)	34,414
Stillbirths (SB)	171
Total births	34,585
Number of terminations of pregnancy (ToP) for birth defects	209

Birth Defects	Number of cases			Rates*10,000
	LB	SB	ToP	Total rate
Anencephaly	0	1	12	3.76
Spina bifida	3	0	20	6.65
Encephalocele	1	0	< 5	1.45
Microcephaly	9	0	0	2.60
Holoprosencephaly	0	0	< 5	0.87
Hydrocephaly	13	1	24	10.99
Anophthalmos	0	0	0	0.00
Microphthalmos	2	0	0	0.58
Unspecified Anophthalmos/Microphthalmos	0	0	0	0.00
Anotia	0	0	0	0.00
Microtia	2	0	0	0.58
Unspecified Anotia/Microtia	0	0	0	0.00
Transposition of great vessels	11	1	< 5	4.05
Tetralogy of Fallot	13	0	< 5	4.34
Hypoplastic left heart syndrome	5	1	7	3.76
Coarctation of aorta	20	1	< 5	6.36
Choanal atresia, bilateral	1	0	0	0.29
Cleft palate without cleft lip	27	0	< 5	8.96
Cleft lip with or without cleft palate	37	0	7	12.72
Oesophageal atresia/stenosis with or without fistula	8	1	< 5	2.89
Small intestine atresia/stenosis	9	0	0	2.60
Anorectal atresia/stenosis	8	0	< 5	3.47
Undescended testis (36 weeks of gestation or later) (§)	20	0	0	5.78
Hypospadias (#)	60	0	< 5	17.64
Epispadias	0	0	0	0.00
Indeterminate sex	3	0	0	0.87
Renal agenesis	1	0	9	2.89
Cystic kidney	24	1	7	9.25
Bladder exstrophy	1	0	0	0.29
Polydactyly, preaxial	1	1	0	0.58
Total Limb reduction defects (include unspecified)	18	5	8	8.96
Transverse	10	3	4	4.92
Preaxial	2	0	0	0.58
Postaxial	0	0	0	0.00
Intercalary	3	1	< 5	1.73
Mixed	2	0	< 5	0.87
Unspecified	1	1	1	0.87
Diaphragmatic hernia	8	0	5	3.76
Omphalocele	4	1	10	4.34
Gastroschisis	12	0	< 5	3.76
Unspecified Omphalocele/Gastroschisis	0	0	< 5	0.29
Prune belly sequence	0	0	0	0.00
Trisomy 13	2	0	5	2.02
Trisomy 18	6	1	19	7.52
Down syndrome, all ages (include age unknown)	34	2	45	23.42
<20	3	0	< 5	13.19
20-24	4	0	< 5	7.68
25-29	3	0	< 5	7.50
30-34	8	1	10	22.40
35-39	5	1	20	52.74
40-44	10	0	8	189.67
45+	1	0	0	212.77
unknown	0	0	0	---

(*) Number for ToPs < 5 is not reported
(§) Undescended testes includes only cases requiring surgery
(#) Hypospadias includes all cases

Wales: CARIS, Previous years rates 1998 - 2007

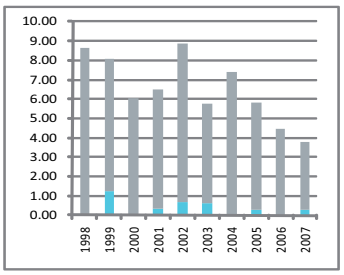
Birth prevalence rates: (LB+SB+TOP) * 10,000

	1974-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007
Total births						**158,475**	**164,987**
Anencephaly						7.64	5.39
Spina bifida						8.52	7.03
Encephalocele						2.21	2.00
Microcephaly						7.07	3.88
Holoprosencephaly						1.26	1.58
Hydrocephaly						10.29	8.97
Anophthalmos						0.50	0.24
Microphthalmos						2.33	1.15
Unspecified Anophthalmos / Microphthalmos						0.00	0.00
Anotia						0.32	0.12
Microtia						0.57	0.67
Unspecified Anotia / Microtia						0.00	0.00
Transposition of great vessels						5.30	4.06
Tetralogy of Fallot						2.97	3.58
Hypoplastic left heart syndrome						3.47	3.45
Coarctation of aorta						6.37	6.00
Choanal atresia, bilateral						0.13	0.30
Cleft palate without cleft lip						9.97	9.39
Cleft lip with or without cleft palate						9.91	11.27
Oesophageal atresia / stenosis with or without fistula						3.60	2.97
Small intestine atresia / stenosis						1.96	1.94
Anorectal atresia / stenosis						5.17	2.85
Undescended testis (36 weeks of gestation or later)						6.94	5.58
Hypospadias						27.51	22.30
Epispadias						0.50	0.24
Indeterminate sex						0.44	0.91
Renal agenesis						2.71	2.00
Cystic kidney						10.85	9.03
Bladder exstrophy						0.38	0.12
Polydactyly, preaxial						1.26	0.85
‘Total Limb reduction defects (include unspecified)						10.98	8.85
Transverse						4.86	4.79
Preaxial						1.77	1.03
Postaxial						0.69	0.18
Intercalary						1.77	1.64
Mixed						0.95	0.91
Unspecified						1.39	0.73
Diaphragmatic hernia						3.79	3.88
Omphalocele						3.53	4.36
Gastroschisis						4.61	7.09
Unspecified Omphalocele / Gastroschisis						0.69	0.30
Prune belly sequence						0.19	0.06
Trisomy 13						2.65	1.82
Trisomy 18						4.29	6.18
Down syndrome, all ages (include age unknown)						19.88	22.37
<20						9.69	7.17
20-24						7.52	7.56
25-29						12.27	8.62
30-34						16.47	17.86
35-39						51.87	60.63
40-44						167.42	167.56
45+						258.06	434.78
unknown						---	---

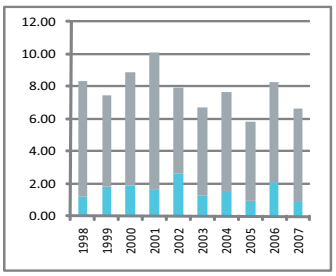
Wales: CARIS

'Time trends 1998-2007 (Birth prevalence rates per 10,000)

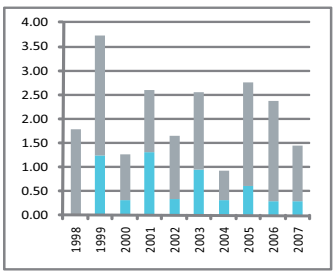
Anencephaly



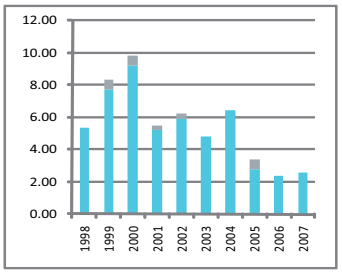
Spina Bifida



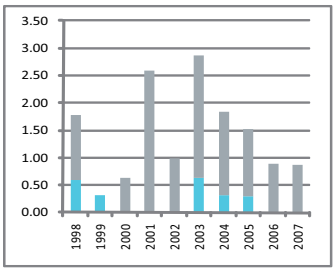
Encephalocele



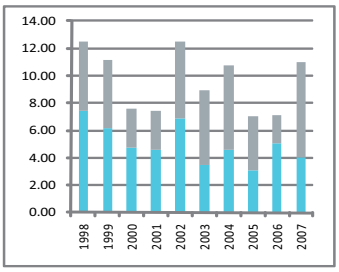
Microcephaly



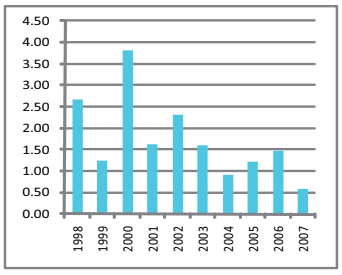
Holoprosencephaly



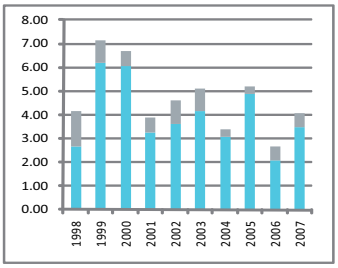
Hydrocephaly



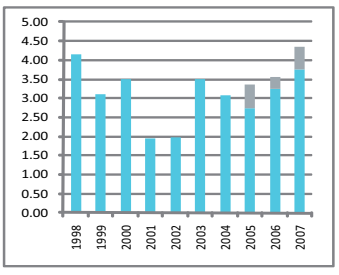
Microphthalmos



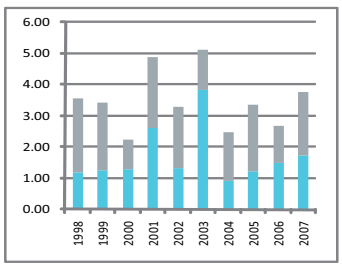
Transposition of great vessels



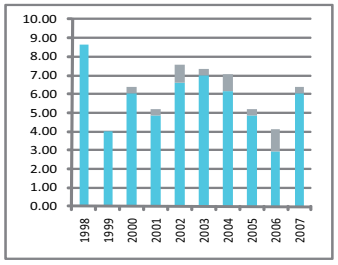
Tetralogy of Fallot



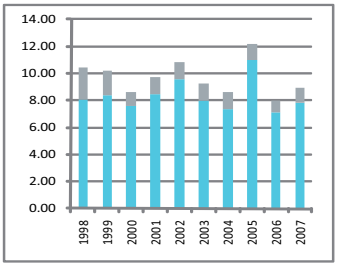
Hypoplastic left heart syndrome



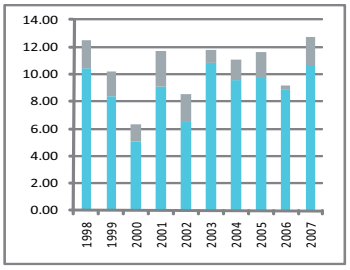
Coarctation of aorta



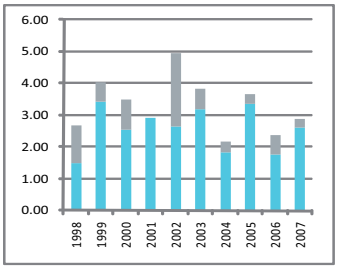
Cleft palate without cleft lip



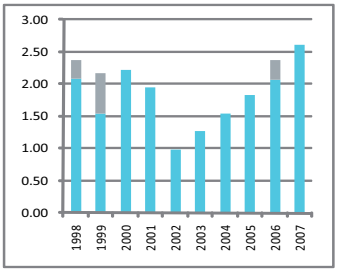
Cleft lip with or without cleft palate



Oesophageal atresia/stenosis with or without fistula



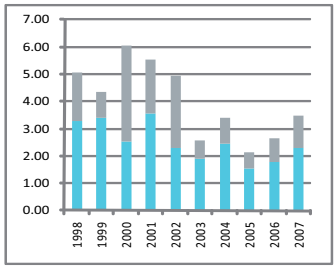
Small intestine atresia/stenosis



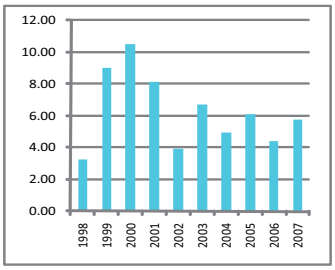
Note: L+S rates, ToP rates

Wales: CARIS

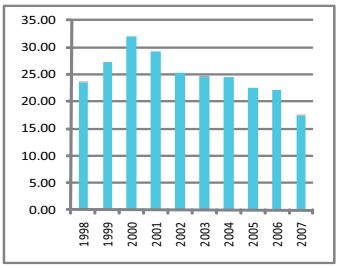
Anorectal atresia/stenosis



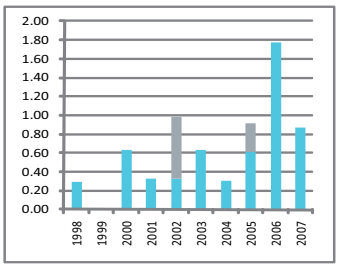
Undescended testis



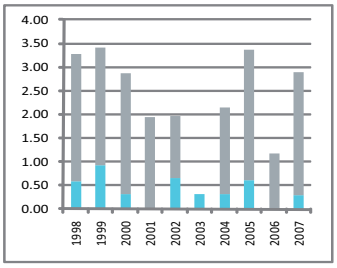
Hypospadias



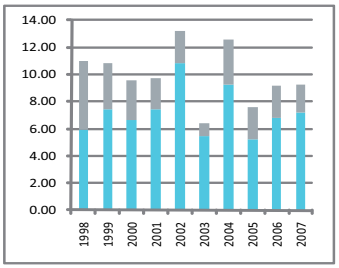
Indeterminate sex



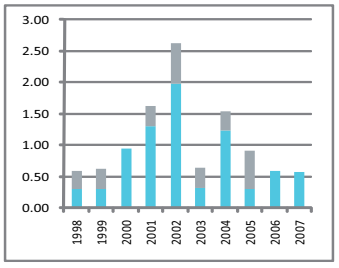
Renal agenesis



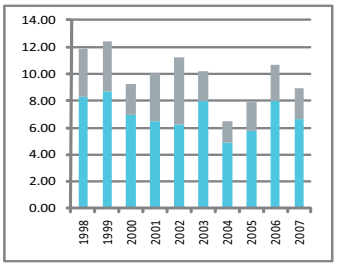
Cystic kidney



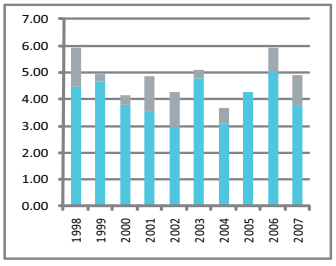
Polydactyly, preaxial



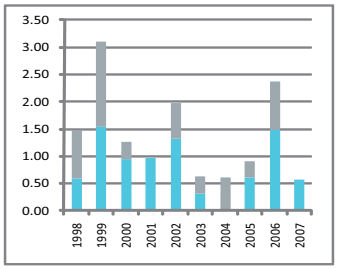
Limb reduction defects



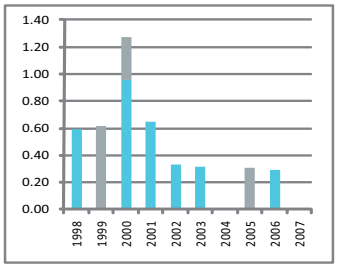
Limb reduction defects - transverse



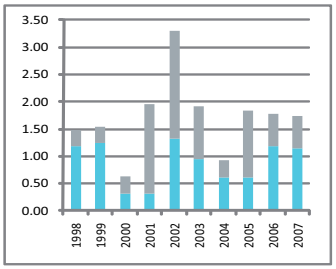
Limb reduction defects - preaxial



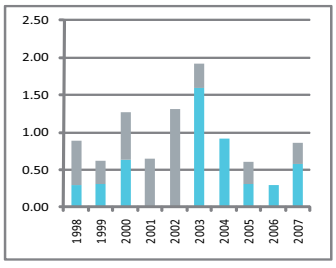
Limb reduction defects - postaxial



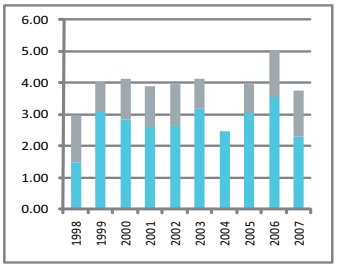
Limb reduction defects - intercalary



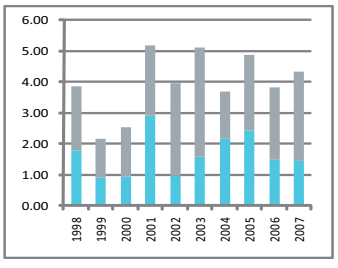
Limb reduction defects - mixed



Diaphragmatic hernia



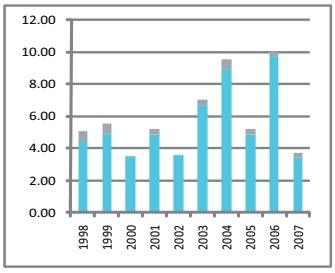
Omphalocele



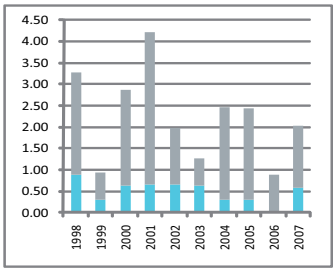
Note: L+S rates, ToP rates

Wales: CARIS

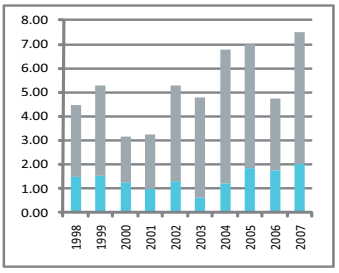
Gastroschisis



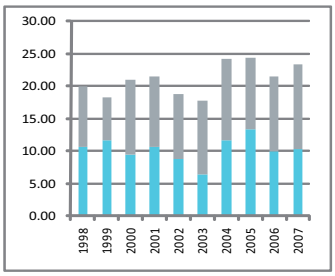
Trisomy 13



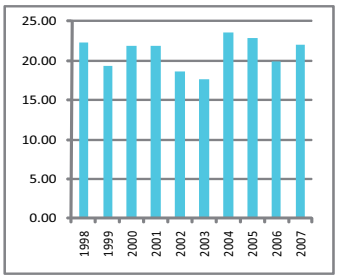
Trisomy 18



Down Syndrome



Down Syndrome standardized total rate



Note: L+S rates, ToP rates

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

Australia - National: ACAMS

Australian Congenital Anomalies Monitoring System

History:
The mechanism for national monitoring of birth defects in Australia was established in 1981. The national programme became an associate member of the Clearinghouse in 1982 and full member in 1984. Australia has not contributed national data to the Clearinghouse for the last 3 years.
In Australia, the data have been provided to the national program by the state and territory health authorities primarily from their birth defects registers and perinatal data collections. However there are variations among state and territory data collections, in the definitions and classifications used, the duration of collection and the level of ascertainment. Therefore Australia has reviewed the existing system and has undertaken a project to develop a new system. They anticipate the resumption of data contribution to the ICBDSR in the foreseeable future.

Size and coverage:
All births of at least 20 weeks gestation or at least 400 grams birthweight in Australia are covered. In 2005, there were 272,419 births in Australia, an increase of 5.9% from the number reported in 2004.

Legislation and funding:
There is no national legislation requiring the reporting of birth defects at the national level. In some States, notification to their birth defect registry is required as part of their respective Public Health Acts. In some States and Territories, birth defect data is collected as part of another collection, and funding, if any is determined by the jurisdiction. The State and Territory Health Departments report to the AIHW National Perinatal Statistics Unit which is the national data custodian of the congenital anomalies data collection. The current funding for development of a national minimum dataset for the congenital anomalies is from the Australian Health Ministers Advisory Committee.

Sources of ascertainment:
The State and Territory birth defect data collections operate independently and there is enormous variation in the breadth of notification sources and level of ascertainment. Other sources of notification may include death certificates, autopsies, hospital morbidity databases, notification from health professionals, cytogenetic and prenatal screening. At the minimum, State and Territory birth defect registries and perinatal data collections send electronic notification to the central data custodian annually.

Exposure information:
Currently not available.

Background information:
In the absence of national legislation, there is variation in the scope, quality of data and ascertainment between the States and Territories. Under the current development project, Australia is working on development of an agreed national minimum data set for congenital anomalies. It's program of work also includes the development of clinical definitions for congenital anomalies a review of the scope of the collection and development of a nationally consistant classification system.

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China: BDSS-Beijing

Birth Defect Surveillance System in Thirty Counties of Four Provinces, People's Republic of China

History:
The Programme began in 1992. It became a full member of the ICBDSR in 1997.

Size and coverage:
This is a population based monitoring system. Reports were obtained from all hospitals and village health stations, which together cover all geographically defined population. Total number of population in these areas is around 17 millions and total number of births per year is around 150,000.

Legislation and funding:
Funding is from China Ministry of Health and local Health Authorities.

Sources of ascertainment:
Reports are obtained from delivery units, paediatric clinics, ultrasound departments, pathology departments and perinatal health care departments of different level hospitals, MCH institutes and village health stations in the participating counties and cities.

Exposure information:
Exposure information is obtained from the perinatal health care surveillance system (PHCSS) in the same areas for all women and their babies from pre-marital examination till six weeks after birth. BDSS data is linked with PHCSS data by using an ID number assigned to each woman.

Background information:
Background information is also obtained from PHCSS data.

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China: CBDMN

Chinese Birth Defects Program of Sichuan Province, China (until 1994)
Chinese Birth Defects Monitoring Network

History:
The Programme began in 1984. It became an associate member of the ICBDMS in 1985 and a full member in 1987.

Size and coverage:
In 1984, reports were obtained from 100 hospitals but participation has increased. In 1985,205 hospitals participated. At present, the Programme covers approximately 260,000 births annually in 31 provinces.
Since we resumed reporting data, only one part of data (20 provinces, I remember apprising you by email several years ago) is sent to ICBD. The nationwide programme covers approximately 450,000~500,000 births annually in provinces.

Legislation and funding:
Participation is voluntary. Funding is mainly from local health authorities, also supported by Ministry of health.

Sources of ascertainment:
Reports are obtained from delivery units, paediatric clinics, and pathology departments of the participating hospitals.

Exposure information:
Exposure information is obtained by interviews of mothers of the reported malformed infants. No information is available on exposures in controls.

Background information:
Total number of births from each participating hospital is known.

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Costa Rica: CREC
Costa Rican Birth Defects Register Center

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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England and Wales
National Congenital Anomaly System

History:
The monitoring programme was started in 1964. It was a founding member of the Clearinghouse.

Size and coverage:
All births in England and Wales are covered, at present approximately 649,000 annually. Stillbirths of 24 weeks or more gestation are registered.

Legislation and funding:
Reporting is voluntary. The governmental Office for National Statistics finances the National Congenital Anomaly System.

Sources of ascertainment:
Reports are mainly based on notifications of births prepared by attendants at birth, either physicians or midwives by means of a paper form (the SD56 form). This form contains a written description of the anomaly and details of the birth, along with some demographic information about the parents. In areas covered by local congenital anomaly registers this information is supplemented by other reports from neonatal intensive care units, special care baby units etc.

It has long been recognised, however, that there is under reporting in NCAS. Therefore NCAS has embarked on an on-going programme of improving the level of reporting to the system. Since 1998, local congenital anomaly registers have begun to provide data to NCAS in each of the years detailed below:

1998	CARIS (Wales)
1999	East Midlands & South Yorkshire Congenital Anomaly Register
2000	North Thames (West) Congenital Malformation Register
2000	Merseyside and Cheshire Congenital Anomaly Survey
2002	Wessex Antenatally Detected Anomalies Register (WANDA)
2002	Congenital Anomaly Register for Oxfordshire, Berkshire & Buckinghamshire (Oxfordshire only prior to 2004)
2003	Northern Congenital Abnormality Survey
2003	South West Congenital Anomaly Register

In 2005, congenital anomaly notifications are now received for all births in Wales and 45 per cent of births in England. For areas for which NCAS relies solely on SD56 notification forms recording is likely to be less complete.

Reports of terminations of pregnancy have been compiled from notifications of abortions that are completed by the operating practitioners under the 1967 Abortion Act and are sent to the Chief Medical Officers of England and Wales. The tables sent to the International Clearinghouse only include notifications of abortions performed under Grounds E of the Act. An abortion may be performed under Grounds E if 'there is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'. Since April 2002, the Department of Health has been responsible for the processing of the abortions notification forms and information has been made accessible to the Office for National Statistics (ONS) for statistical purposes.

Exposure information:
Parents' occupation is known.

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Italy - Sicily: ISMAC

Sicilian Registry of Congenital Malformations

History:
The registry started in 1991 and became an associate member of the Clearinghouse in 1996.

Size and coverage:
The Programme is hospital based and actually collaborates with four south-east provinces (Catania, Enna, Ragusa and Siracusa) of the nine Sicilian provinces, with a covering rate higher than 75% and with more than 19,000 controlled newborns for year. Stillbirths are included.

Legislation and funding:
The Programme is a surveillance Programme with a voluntary participation, supported by ASMAC-Associazione per la Prevenzione Sociale e per il Trattamento delle Malformazioni Congenite and under Osservatorio Epidemiologico Regionale-Sicilia.

Sources of ascertainment:
Reports are obtained from delivery units, pediatric units and other specialistic departments.

Exposure information:
For each malformed infant reported, information is given on certain exposures, including maternal drug usange and parental occupation. Up to now no information on controls is available.

Background information:
Up to now little background information is available and no information on controls is available.

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Italy Lombardy: RMCL

Congenital Malformation Registry of Northern Lombardy

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

Size and Coverage:
The Registry is population-based and registers about 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.

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Congenital Malformation Registry of Northern Lombardy (CMRL)
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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

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Germany: Saxony-Anhalt

Bade, A., Rohden, L. von, Hoyer-Schuschke, J., Pötzsch, S. Ultraschallscreening des Schädels bei Neugeborenen - Pro und Kontra. In: Päd Praktische Pädiatrie 14 (2008), 3, 178-188

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Texas (Local Study) - Manuscripts under review

Hashmi SS, Gallaway MS, Waller DK, Langlois PL, Hecht JT. Maternal Fever during Pregnancy and the risk of Oral Clefts.

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