B D R News

The official newsletter of The Birth Defects Registry of India, (A Unit of Fetal Care Research Foundation)

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Proceedings of the Chennai Birth Defects Registry meeting held on the 24th of April 2003.

The II meeting of the year was held on the 24th April 2003 at Mediscan Systems. Members of Chennai BDR (CBDR) had assembled in appreciable number to gather information on birth defects prevalence in Chennai Metropolis last year in a sample population. Dr. S.Suresh welcomed the audience. He noted that an elaborate analysis of the data collected during last year has been made and some of the salient features in annual statistics have been compared with previous year. He emphasized the need to have a larger membership so as to enhance the validity of the statistics on birth defects. He appreciated and thanked the gesture of Dr.Deivanai, Population Project Control Officer, Chennai Corporation for approving the enrollment of all corporation hospitals in all the zones in Chennai. They are in the process of getting inducted shortly. He also thanked Dr. Usha Viswanathan (Registrar - SRMC) for her efforts in motivating obstetricians at Trichy who have agreed to start a registry very soon.

Dr.G.Thangavel presented the annual statistics of birth defects with a short note on the modifications made in the registry forms, which indeed would simplify the process of data entry for the members. He explained the rationale behind the modifications and he assured that the new forms are consistent with the forms of other birth defects registries abroad. He also observed that our combined venture has resulted in bringing out the statistics successively for the II year. This collaborative process has been accomplished without external funding or additional manpower but only a little extra time and the strong commitment of all member hospitals. However, we foresee that mobilization of funds in future would facilitate smooth growth and expansion of the registry.

Chennai Birth defects registry, Second annual report - Year 2002

Dr.G.Thangavel, Epidemiologist, Birth Defects Registry of India (BDRI)

Introduction:

Birth defects registry of India (BDRI) was established in 2001 with an objective of estimating the birth prevalence of congenital malformations in India by establishing birth defects registries across the country. Chennai birth defects registry (CBDR) was initiated in the same year as the first offshoot of BDRI. Birth defects registries are of two types, a. Descriptive and b. Analytical. In Descriptive BDR, prevalence, secular trends and cluster occurrence of birth defects are analysed. In Analytical BDR, etiological analysis is done with the data collected and preventive measures are brought out by intervention and evaluation.

CBDR is a hospital-based registry, which collects data on births/ birth defects from 19 hospitals in Chennai metropolis. The 19 hospitals that participate in the registry voluntarily send the data to CBDR. Once the registry receives the data, they are scrutinized by the Dysmorphologist and stored in a database. The diagnostic terms are then coded according to ICD10 published by WHO for maintaining uniformity and easy retrieval. The data are then subjected to statistical analysis and the yearly annual report is presented to the participatory members. Given below is the second annual report of the registry.

Section 1: Section I of the second annual report from Chennai birth defects registry presents the prevalence of congenital malformations occurring among 15,077 births with normal /abnormal outcome in 19 participating hospitals in the year 2002. Table 1 shows number of congenitally malformed babies in various categories of births and their prevalence.

Table 1: Categories of birth prevalence of congenitally malformed babies

Category	N	%	Number of babies with CM*	Prevalence /1000
Live births	14,840	98.4	112	7.5
IUD / SB	160	1.1	18	112.5
MTP	77	0.5	77	5.1
Total births	**15,077**	**100**	**207**	**13.73**

* Congenital malformation

Missed or spontaneous abortions and medical termination of pregnancy (MTP), which was done for parent's option (other than for anomaly), are not included either in the numerator or denominator

Section 2:

Section 2: Section 2 presents the system specific and anomaly specific prevalence and the sex ratio of anomalies. ***Analysis of Data:*** The prevalence of anomalies was calculated in the following manner. If two or more anomalies were present in the same fetus/child, each anomaly was counted separately for calculating prevalence of particular anomaly. For e.g., if a fetus/child had talipes, omphalocele and ventricular septal defect (VSD), the anomaly count would be three for the fetus/child. If system wise prevalence was calculated for the same child, the count would be two i.e. omphalocele and talipes were classified under musculoskeletal and VSD, under circulatory system. Therefore the total number of individual/system anomalies would not add up to give the total number of fetuses or children. Isolated anomalies were not

distinguished in the results from anomalies that form part of syndromes or multiple malformations. Prevalence in each participating center was not analyzed. Table 4 presents the prevalence of each individual anomalies and their sex ratio. The following tables (Table 2 & 3) show the system specific & anomaly specific prevalence of major anomalies in Chennai during the year 2002.

Table 2: Prevalence of system specific major anomalies

System	N	Prevalence /1000
Musculoskeletal	66	4.4
Central nervous	56	3.7
Circulatory	46	3.1
Genitourinary	38	2.5
Gastrointestinal	31	2.1
Respiratory	9	0.6
Facial	7	0.5
Others	8	0.5

Table 3: Prevalence of selected major anomalies

Anomaly	N	Prevalence /1000
Neural tube defects	41	2.72
Congenital talipes equinovarus	23	1.5
Cleft palate/Cleft lip	20	1.3
Limb reduction defects	15	1
Ventricular septal defects	13	0.9
Atrial septal defects	13	0.9
Omphalocele	8	0.5
Cystic kidney diseases	8	0.5
Down syndrome	5	0.3

Table 4: Prevalence distribution of all anomalies

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
A. Congenital Anomalies of the Central Nervous System (Q00 – Q07)	**57**	**3.8**	**1:1.6**
A01 Anencephaly (Q00.0) (Incl. Acrania)	21	1.4	1:1.6
A02 Encephalocele (Q01.0 – Q01.9) (Incl. Frontal & Occipital Encephalocele/ Meningocele)	6	0.4	1:4
A03 Microcephaly (Q02)	1	0.07	-
A04 Congenital Hydrocephalus without Spina bifida (Q03.0 – Q03.9) (Incl. Dandy – Walker malformation, Ventriculomegaly)	7	0.5	1:2
A05 Spina bifida without anencephaly (Q05.0 – Q05.9) (Incl. Meningocele, Meningomyelocele, Myelocele, Rachischisis, excluding Spina bifida occulta)	14	1	1:1
A06 Holoprosencephaly (Q04.2)	5	0.3	1:1.5
A07 All other congenital malformations of brain, spinal cord & nervous system (Q04 & Q06) (Incl. Agenesis of corpus collosum, absence of nerves, cerebral cysts and cerebellar malformations, etc.)	6	0.5	1:2

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
B. Congenital Anomalies of Eye, Ear, Face & Neck (Q10 – Q18)	**22**	**1.5**	**1:1.5**
B01 Anopthalmos / Micropthalmos / Macropthalmos (Q11.0 – Q11.9)	5	0.4	1.5:1
B02 Congenital Corneal opacity (Q13.3)	1	0.07	-
B03 Low set ears (Q17.4)	16	1.1	1:1.3
B04 All other congenital anomalies of Eye, Ear, Face & Neck (Q10 – Q18) (Incl. Imperforate auditory meatus)	4	0.3	2:1

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
C. Congenital Anomalies of the Circulatory System (Q20 – Q28)	**52**	**3.4**	**1.04:1**
C01 Common Truncus / Persistent Truncus arteriosus (Q20.0)	1	0.07	-
C02 Double outlet right ventricle (Q20.1)	5	0.3	1:3
C03 Other congenital malformations of cardiac chambers (Q20.8)	1	0.07	-
C04 Ventricular Septal Defect (Q21.0)	13	0.9	2.25:1
C05 Atrial Septal Defect / Patent or persistent foramen ovale (Q21.1)	13	0.9	1:1.6
C06 Atrioventricular septal defect / Endocardial Cushion Defect / Ostium primum (Q21.2)	3	0.2	1:2
C07 Tetrology of follot (Q21.3)	3	0.2	3:0
C08 Other congenital malformations of cardiac septa (Q21.8 & Q21.9)	1	0.07	-
C09 Ebstein's anomaly (Q22.5)	1	0.07	-
C10 Hypoplastic right heart syndrome (Q22.6)	1	0.07	-
C11 Bicuspid aortic valve (Q23.1)	1	0.07	-
C12 Hypoplastic left heart syndrome (Q23.4)	6	0.4	1:1
C13 Patent ductus arteriosus (Q25.0)	3	0.2	2:1
C14 Coarctation of aorta (Q25.1)	2	0.1	1:1
C15 Other congenital malformation of aorta (Q25.4)	1	0.07	-
C16 Stenosis of pulmonary artery (Q25.6)	1	0.07	-
C17 Single umbilical artery (Q27.0)	9	0.6	1:3

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
D. Respiratory system (Q30 – Q34)	**9**	**0.6**	**1:2**
D01 Agenesis of nose (Q30.1)	1	0.07	-
D02 Congenital cystic lung (Q33.0)	2	0.1	2:0
D03 Hypoplastic lung (Q33.6)	6	0.4	1:5

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
E. Congenital anomalies of the Gastro Intestinal Tract (Q35 – Q45)	**41**	**2.7**	**1:2.2**
E01 Cleft palate (Q35.0 – Q35.9)	5	0.3	1:1.5
E02 Cleft lip (Q36.0 – Q36.9)	5	0.3	1:1.5
E03 Cleft palate & cleft lip (Q37.0 – Q37.9)	10	0.7	1:2.3
E04 High arched palate (Q38.5)	5	0.3	1:4
E05 Other congenital malformations of tongue and mouth (Q38.3, Q38.6)	3	0.2	0:3
E06 Atresia of oesophagus without fistula (Q39.0)	3	0.2	2:1
E07 Tracheo-oesophageal fistula without atresia (Q39.2)	2	0.1	1:1
E08 Absence, atresia and stenosis of small intestine (Q41.0 – Q41.9)	1	0.07	-
E09 Imperforate anus (Q42.3)	5	0.3	2.5:1
E10 Other Congenital malformations of intestines (Q43.0 - Q43.9)	4	0.3	0:4
E11 Congenital malformations of liver (Q44.6, Q44.7)	2	0.1	0:2

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
F. Congenital Anomalies of the Genital and Urinary Systems (Q50 – Q64)	**40**	**2.7**	**1:1.1**
F01 Congenital malformation female genital organs (Q50.0 – Q52.9)	2	0.1	-
F02 Undescended testis (Q53.0 – Q53.9)	4	0.3	-
F03 Hypospadias (Q54.0 – Q54.9)	4	0.3	-
F04 Other congenital malformations of male genital organs (Q55.0 – Q55.9)	2	0.1	-
F05 Indeterminate sex (Q56.4)	6	0.4	-
F06 Renal agenesis (Q60.0 – Q60.6)	5	0.3	3:1
F07 Cystic kidney disease (Q61.0 – Q61.9) (Incl. Infantile or Adult polycystic kidney and Multicystic dysplasia)	8	0.5	1:7
F08 Congenital hydronephrosis (Q62.0)	2	0.1	2:0
F09 Pelviureteric junction obstruction	1	0.07	-
F10 Other congenital obstructive defects of renal pelvis & Ureter (Q62.3)	1	0.07	-
F11 Other congenital malformations of kidney (Q63.0 - Q63.9) (Incl. Fused / Horseshoe kidney)	3	0.2	1:2
F12 Congenital posterior urethral valve (Q64.2)	3	0.2	-
F13 Other congenital malformations of bladder & urethra (Q64.3)	2	0.1	0:2

***** Details of the sex differentiation not available for denominator population***

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
G. Congenital Anomalies of the Musculoskeletal System (Q65 – Q79)	**83**	**5.5**	**1:1.26**
G01 Talipes equinovarus (Q66.0)	23	1.5	1:1.3
G02 Other Congenital malformations of feet (Q66.1- Q66.9) (Incl. Rocker bottom foot)	11	0.7	1:1.2
G03 Congenital Musculoskeletal deformities of head, face, spine & chest (Q67.0 – Q67.9) Incl. Dysmorphic face (Q67.0)	5	0.3	1:4
G04 Congenital deformities of knee (Q68.2) Genu recurvatum	2	0.1	0:2
G05 Other specified congenital musculoskeletal deformities (Q68.8) (Deformity of clavicle, elbow, forearm, scapula, femur, tibia, fibula)	3	0.2	1:1
G06 Polydactyly (Q69.0 – Q69.9)	4	0.3	3:1
G07 Syndactyly and polysyndactyly (Q70.0 – Q70.9)	7	0.5	2.5:1
G08 Upper limbs - reduction defects / shortening (Q71.0 – Q71.9)	6	0.4	1:2
G09 Lower limbs - reduction defects / shortening (Q72.0- Q72.9)	3	0.2	1:2
G10 Unspecified limbs - reduction defects / shortening (Q73.0 – Q73.8)	6	0.4	2:1
G11 Arthrogryposis (Q74.3)	3	0.2	1:2
G12 Other congenital malformations of limbs (Q74.8 & Q74.9)	6	0.4	1:1
G13 Hypertelorism (Q75.2)	10	0.7	1:8
G14 Other congenital malformations of skull & face bones (Q75.0– 75.9)	14	0.9	1.4:1
G15 Spina bifida occulta (Q76.0)	1	0.07	-
G16 Scoliosis due to hemivertebra (Q76.3)	1	0.07	-
G17 Other congenital malformations of bony thorax (Q76.8)	1	0.07	-
G18 Osteochondrodysplasia with defects of growth of tubular bones & spine (Q77.0 – Q77.9)	2	0.1	0:2
G19 Osteogenesis imperfecta (Q78.0)	2	0.1	0:2
G20 Diaphragmatic Hernia (Q79.0)	4	0.3	1:2
G21 Absence / Eventration of diaphragm (Q79.1)	2	0.1	2:0
G22 Exomphalos / Omphalocele (Q79.2)	8	0.5	1:1.3
G23 Gastroschisis (Q79.3)	1	0.07	-
G24 Prune belly syndrome (Q79.4)	1	0.07	-
G25 Other congenital malformations of abdominal wall (Q79.8, Q79.9) (Incl. Limb body wall complex)	2	0.1	1:0

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
H. Other Congenital Anomalies (Q80 – Q86 & Q89)	**12**	**0.8**	**1.4:1**
H01 Abnormal palmar creases (Q82.8)	3	0.2	2:1
H02 Congenital Hypothyroidism (Q89.2)	3	0.2	2:1
H03 Absent / Hypolastic thymus (Q89.8)	3	0.2	1:2
H04 All other congenital malformations not elsewhere classified (Q89.9)	3	0.2	2:1

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
I. Multisystem Anomalies / Syndromes	**6**	**0.4**	**1:1**
I01 Goldenhar syndrome (Q87.0)	1	0.07	1:0
I02 Pierre Robin syndrome (Q87.0)	2	0.1	0:2
I03 Meckel Gruber Syndrome (Q61.9)	1	0.07	0:1
I04 Other Syndromes (Q87.9)	2	0.1	2:0

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
J. Chromosomal Anomalies (Q90)	**9**	**0.6**	**2:1**
J01 Down's Syndrome (Q90.0 – Q90.9)	5	0.3	1.5:1
J02 Edwards' Syndrome & Patau's syndrome (Q91.0 – Q91.9)	3	0.2	3:0
J03 Triploidy (Q92.7)	1	0.07	0:1

Summary:

Dr. G. Thangavel concluded his presentation with the following summary :-

- System wise analysis revealed that musculoskeletal anomalies are the most common in the population analyzed.
- NTD is the single most occurring anomaly. The sex ratio (male:female) of anencephaly as compared to last year has changed from 2:1 to 1:1.6 .
- Prevalence of folic acid preventable anomalies is 5.3/1000. In actual number it could be 663 babies in our city alone in a given year. Assuming that folic acid has 60% preventive value, in the present context, 398 babies can be saved by periconceptional folic acid.
- Antenatal ultrasonography has brought down the live birth prevalence of central nervous system anomalies, as they are detected prenatally and electively terminated.

During discussion, questions were raised as to whether birth defects analysis in terms of major & minor anomalies was done in live births? This was not done at present and the total prevalence of anomalies in live births accounted for 5.6/1000. The other query was concerning the five cases of Down's syndrome reported this year. The query was whether they were prenatally diagnosed? Of the five cases, two were prenatally diagnosed, one was TST positive and amniocentesis proved Trisomy 21 and the other case was a rare presentation of Down's with Myelodysplasia proved by fetal blood sampling. Among the rest, two were live births, whose karyotype proved the presence of T21 and one other baby had classical clinical features of Down's syndrome.

An appeal

Help a national cause Join the Birth defects registry. If you are already a member of the registry, please motivate a friend to become a member of the registry. If you are not a member kindly contact us. Let us work together to build a healthier nation.

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