BDR NEWS

The official newsletter of The Birth Defects Registry, Chennai

(Unit of Fetal Care Research Foundation)

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Proceedings of the meeting of Chennai Birth Defects Registry held on the 16th of April 2002

The annual meeting of the registry was held on the 16th of April 2002 at Fetal Care Research Foundation, Chennai. Dr.S.Suresh, in his welcome address acknowledged the sincere participation of member hospitals over a period of one year, which has made possible the creation of a comprehensive data on birth defects. He expressed his hopes saying that this pioneering attempt would soon spread at a faster pace and the registry would become a large body to provide more authentic source of information on birth defects. As the saying goes "Little drops of water make a mighty ocean". Let us hope that our small efforts would make a National Registry possible in the near future. Various hospitals in TamilNadu and other states have been approaching us for guidelines to start a registry in their respective regions.

Dr. Sujatha Jagadeesh discussed many issues related to the functioning of the registry. She elicited views of the members on the BDR forms and whether they were user friendly. She also wanted the members to give a feed back about the newsletters and requested their active contribution for publication every month. She called for more involvement of the pediatric personnel in all the member hospitals in registering birth defects, as our registry collects data up to one year of age. Each member was requested to induct two new members in the current year for a wider coverage. The statistical data revealed that our registry has covered only 11.33% births in Chennai. Hence there is a need to involve more hospitals. She concluded her talk by informing that BDR will be launching health education programs related to the prevention of Neural Tube Defect and Rubella in collaboration with the Inner Wheel club of Rotary Madras Central very soon. The data obtained from BDR would give all the members hope for further research. Dr.Thangavel presented the annual BDR statistics.

Chennai Birth defects registry, First annual report

Dr.G.Thangavel, Consultant epidemiologist, Fetal Care Research Foundation

Background:

The true magnitude of the birth defects in India is not known, though birth defects were studied in India as early as 1963[1], coinciding with the thalidomide tragedy in the West[2]. Unlike in the West, where the leading cause of infant mortality is birth defects[3], in India, still low birth weight, prematurity, sepsis & infections are the leading causes of neonatal & infant mortality[4]. Perhaps for this reason we in India have not given much attention to the problem of birth defects. However, a few hospital-based studies were published sporadically on birth defects; they were observations on a smaller sample size[1,5-7], or done over a short period of time[7], or based on births occurred in one hospital[7,8]. A few of them were done to ascertain the prevalence of neural tube defects[5,9,10] only. The results of these studies vary with each other indicating the geographical variation of birth defects in India. But the results of these studies cannot be extrapolated to the population; nevertheless they indicate a higher prevalence of birth defects in India as compared to the West. This situation warrants the need of an organized body to continuously monitor for birth defects in India. Hence, Fetal Care Research Foundation (FCRF) a non-profit charitable trust started the National Birth Defects Registry (BDR) in the year 2001. As part of the National BDR the Chennai registry was initiated at the same time to ascertain the magnitude of the problem posed by birth defects in Chennai metropolis, on an experimental basis. It has inducted about 18 hospitals in the city and collects the data on deliveries occurring in these hospitals. Having had one-year experience in this field, the registry now wants to spread this systematic effort through out the nation.

Summary

The first annual report from the Chennai birth defects registry (Jan-2001-Jan2002) presents the prevalence of congenital malformations occurring among the 14,161 pregnancies with normal /abnormal outcome in the 18 participating hospitals in one year. 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. Because very few missed abortions have been reported as congenitally malformed as against the total number of missed abortions (23/606 = 3.8%) and MTP done for parent's option did not have anomalies, they were excluded from analysis. Table 1 shows the split up of various types of births and their prevalence. Section 2 presents the distribution of system wise anomalies with the total prevalence and sex ratio.

Table.1: Type of deliveries

Type of delivery	Number of births	%	Number of babies with BD*	Prevalence /1000
Live births	13,883	98.1	76	5.5
IUD / SB	201	1.4	33	164.2
MTP for BD*	77	0.5	77	5.4
Total births	14,161	100	186	13.3

**BD – birth defects*

Section 2:

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, 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. Anomalies were coded according to the 10th version of the International Statistical Classification of Diseases, published by World Health Organization, Geneva.

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
A. Congenital Anomalies of the Central Nervous System (Q00 – Q07)	**63**	**4.43**	**1 : 1**
A01 Anencephaly (Q00.0) (Incl. Acrania)	18	1.27	2 : 1
A02 Encephalocele (Q01.0 – Q01.9) (Incl. Frontal & Occipital Encephalocele/ Meningocele)	4	0.28	1 : 3
A03 Microcephaly (Q02)	3	0.21	2 : 1
A04 Congenital Hydrocephalus without Spina bifida (Q03.0 – Q03.9) (Incl. Dandy – Walker malformation, Ventriculomegaly)	11	0.77	1.2 : 1
A05 Spina bifida without anencephaly (Q05.0 – Q05.9) (Incl. Meningocele, Meningomyelocele, Myelocele, Rachischisis, Lipomeningocele excluding Spina bifida occulta)	20	1.4	1 : 2.2
A06 All other congenital malformations of brain, spinal cord & nervous system (Q04 & Q06) (Incl. Agenesis of corpus collosum, Holoprosencephaly, Hydranencephaly, Lissencephaly, Diastematomyelia, Colpocephaly, Choroid plexus cyst, agenesis of nerve, etc)	14	0.98	0

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
B. Congenital Anomalies of Eye, Ear, Face & Neck (Q10 – Q18)	**8**	**0.6**	**1 : 2.7**
B01 Anopthalmos / Micropthalmos / Macropthalmos (Q11.0 – Q11.9)	2	0.14	0 : 2
B02 Cystic Hygroma (Q18.8)	5	0.35	1.5 : 1
B03 All other congenital anomalies of Eye, Ear, Face & Neck (Q10 – Q18) (Incl. Absent eyeballs, Cyclops, Imperforate auditory meatus)	3	0.21	0 : 3

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
C. Congenital Anomalies of the Circulatory System (Q20 – Q28)	**34**	**2.4**	**1 : 1.58**
C01 Common Truncus / Persistent Truncus arteriosus (Q20.0)	1	0.07	-
C02 Double outlet right ventricle (Q20.1)	2	0.14	1 : 1
C03Other congenital malformations of cardiac chambers (Q20.8)	1	0.07	-
C04 Ventricular Septal Defect (Q21.0)	13	0.9	1 : 1
C05 Atrial Septal Defect / Patent or persistent foramen ovale (Q21.1)	8	0.6	1 : 1
C06 Atrioventricular septal defect / Endocardial Cushion Defect / Ostium primum (Q21.2)	2	0.14	1 : 1
C07 Other congenital malformations of cardiac septa (Q21.8 & Q21.9)	1	0.07	-
C08 Pulmonary valve stenosis (Q22.1)	1	0.07	-
C09 Tricuspid valve dysplasia (Q22.8)	1	0.07	-
C10 Mitral atresia (Q23.2)	2	0.14	1 : 1
C11 Hypoplastic left heart syndrome (Q23.4)	4	0.28	1 : 1
C12 Other congenital malformation of heart (Q24.0 – Q24.9) (Rhabdomyoma, Pericardial effusion)	2	0.14	-
C13 Patent ductus arteriosus (Q25.0)	4	0.28	1 : 3
C14 Coarctation of aorta (Q25.1)	1	0.07	-
C15 Hypoplasia of aorta (Q25.4)	3	0.21	2 : 1
C16 Other congenital malformations of great arteries (Q25.8) (Single out flow tact)	2	0.14	-
C17 Single umbilical artery (Q27.0)	5	0.35	1 : 2
C18 Aberrant sub clavian artery, Umbilical vein varix (Q27.8)	2	0.14	-

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
D. Congenital Anomalies of the Respiratory System (Q30 – Q34)	**20**	**1.4**	**13**
D01 Hypoplastic lung (Q33.6)	18	1.27	1 : 1
D02 All other congenital malformations of the respiratory system (Laryngeal atresia, Choanal atresia)	2	0.14	-

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
E. Cleft lip and Cleft palate (Q35 – Q37)	**15**	**1.06**	**1 : 1.4**
E01 Cleft palate (Q35.0 – Q35.9)	8	0.56	1.7 : 1
E02 Cleft palate & cleft lip (Q37.0 – Q37.9)	7	0.49	1 : 2.5

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
F. Congenital Anomalies of the Digestive System (Q38 – Q45)	**18**	**1.27**	**1 : 1**
F01 Atresia of oesophagus w ith tracheo - oesophageal fistula (Q39.1)	1	0.07	-
F02 Small intestinal atresia / stenosis/ absence (Q41.0 – Q41.9)	5	0.35	1 : 1
F03 Large intestinal atresia / stenosis/ absence (Q42.0 – Q42.9)	7	0.49	4 : 1
F04 Congenital malformations of Gall bladder, Bile ducts and Liver (Q44)	4	0.28	1 : 3
F05 All Other congenital malformations of digestive system (Q45)	2	0.14	-

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
G. Congenital Anomalies of the Genital and Urinary Systems (Q50 – Q64)	**45**	**3.2**	**1.9 : 1**
G01 Renal agenesis (Q60.0 – Q60.6) (Incl. Renal hypoplasia)	9	0.63	1 : 1
G02 Cystic kidney disease (Q61.0 – Q61.9) (Incl. Infantile or Adult polycystic kidney, Multicystic renal dysplasia)	16	1.13	1.3 : 1
G03 Obstructive Genitourinary Defects (Q62.0 - Q62.9, Q64.2 & Q64.3)	11	0.77	7 : 1
G04 All other congenital malformations of the urinary system (Q63.8 & Q63.9) (Incl. Fused kidneys, Bladder exstrophy, Hypoplastic bladder)	7	0.49	3 : 1
G05 Ambiguous genetalia (Q56.4)	7	0.49	
G06 Congenital malformations of the male genital organs (Q53, Q54 & Q55) (Incl. Hypospadias, Undescended testis, Etc)	6	**	-
G07 Congenital malformations of the female genital organs (Q50 – Q52) (Incl. Bicornuate & Unicornuate uterus)	2	**	-

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

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
H. Congenital Anomalies of the Musculoskeletal System (Q65 – Q79)	**72**	**5.1**	**1.3 : 1**
H01 Upper Limb Reduction Deformities (Q71.0 - Q71.9) (Incl. Club hands)	10	0.7	1.7 : 1
H02 Lower Limb Reduction Deformities (Q72.0 - Q72.9) (Excl. Club foot / CTEV)	8	0.56	1.7 : 1
H03 Gastroschisis / Omphalocele (Q79.2, Q79.3)	8	0.56	1 : 7
H04 Congenital malformations of the Diaphragm (Q79.0, Q79.1) (Incl. Agenesis, Eventration & Hernia)	12	0.84	1.2 : 1

H05 All Other Congenital Anomalies of the Musculoskeletal System (Q65.0 - Q70.9 & Q73.0 - Q78.9) (Incl. CTEV, Rocker bottom heel, Cranial, Thoracic & Spine abn., Polydactyly, Etc.)	77	5.4	1.3 : 1

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
I. Other Congenital Anomalies (Q80 – Q86 & Q89)	**10**	**0.7**	**0:7**
I01 Congenital malformations of the Spleen (Q89.0)	3	0.21	0:3
I02 Congenital malformations of the Adrenal gland (Q89.1)	4	0.28	0:4
I03 Other congenital malformations not elsewhere classified (Q80 – Q86)	3	0.21	1:2

Diagnostic Grouping	Number of cases	Prevalence / 1000	Male & Female ratio
J. Multisystem Anomalies / Syndromes	**34**	**2.4**	**1 : 1.08**
J01 Arnold chiari malformation (Q07.0)	11	0.77	1 : 1.2
J02 Arthrogryposis multiplex congenita (Q89.0)	3	0.21	-
J03 Bilateral renal agenesis (Q60.1)	3	0.21	1 : 2
J04 All other Multisystem Anomalies / Syndromes	17	1.2	1 : 1

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If you know of any hospital willing to join the registry, please ask them to contact us.
We are available at:

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