B D R News

The official newsletter of The Birth Defects Registry of India,

Volume 4 Issue 2: July 2004

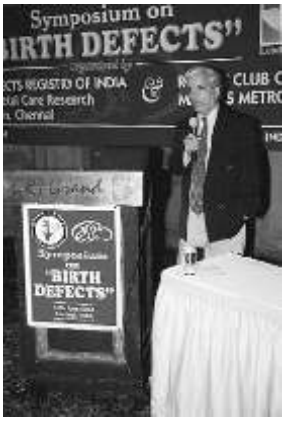
PROCEEDINGS OF THE BIRTH DEFECTS REGISTRY MEETING HELD ON 13TH JUNE 2004

The second meeting of the registry held on the 13th of June this year was a significant one since its inception. There were guest lectures by two dignitaries from the US. The special invitees for the day were Dr. D. Vidyasagar (Neonatologist - Chicago Medical Centre-U.S.A) and Dr. Mary Elizabeth Reeve (Director of Global Perinatal Health Education Programs-March of Dimes Birth Defects Foundation-U.S.A). BDRI along with the Rotary Club of Madras Metro had organized a symposium on birth defects. The Rotary Club of Madras Metro has evinced keen interest to join hands with BDRI for the cause of birth defects. The BDR family wholeheartedly welcomes the Rotary members to tread along with them towards achieving the goals. At the commencement of the meeting Dr. Indrani Suresh (Director BDRI) extended a warm welcome to the audience.

Dr. S. Suresh (Director, Fetal Care Research Foundation) put forth the need for creating registries for birth defects in India. He said that of the 25 million births that occur in our country yearly, more than 2% (i.e >500,000) babies are born with some form of birth defects. This equals the number of Leprosy cases that are detected in India every year. While adequate care has been taken to combat this problem, birth defects have not even been addressed at the primary health care level. An efficient birth defects registry would serve as" Health Intelligence" to disseminate appropriate information on birth defects. As this poses a great socio- economic burden on the families affected and the society at large, Dr.S.Suresh urged the health professionals and the public to get sensitized to this problem. He also acknowledged the advancement in perinatal care at present, which has eventually increased the proportion of birth defects to infant mortality rate (IMR) in India. It is evident that today, IMR due to infectious diseases has come down. He emphasized the need for setting up more perinatal pathology units to improve the skills of sonologists and to give more accurate information to affected parents. He appealed to the medical professionals to give priority for the prevention of "Neural tube defects" which could be done by simple administration of peri-conceptional folic acid. To make the registry viable in the long run he called for the participation of Government Maternity Hospitals and philanthropic contributions from the society for a national cause.

Dr. Sujatha Jagadeesh (Consultant Dysmorphologist-FCRF)in her talk explained the various activities of the organization and said that it is marching with dedication to reach the goals set by the foundation. Dr. G. Thangavel (Epidemiologist-FCRF) presented the annual birth defects statistics of Chennai, Salem and Erode. He observed that Neural Tube Defect was the commonest birth defect found in the sample population in all the above mentioned places. The excerpt of the birth defects statistics presentation is given below.

Dr Usha Sahadevan, Nodal member, Erode Birth Defects Registry (Consultant Obstetrician and Gynaecologist, Lotus Hospital, Erode) narrated her experiences in collection of data from Erode Registry members. She acknowledged the participation of the Erode Government Hospital. She said that an added advantage of data collection is the tremendous improvement in the utilization of perinatal pathology services. She proposes to induct the Rotarians at the district in BDR activities.



Dr. Mary Elizabeth Reeve delivered her presentation on the role of March of Dimes Foundation in the worldwide prevention of birth defects. She said that her foundation has developed partnership programs in many developing nations for the cause of birth defects. Her visit was to explore the possibility of collaborative work with BDRI.

Dr. D.Vidyasagar was instrumental for Dr Mary's visit to Chennai. He said that birth defects contribute to 20% of Infant Mortality Rate in the U.S. Hence this has been considered as a serious issue by the U.S Government. March of Dimes is interested in the global reduction of birth defects as 7.2 / 7.7 million birth defects happen in the developing nations around the world. He said that the philosophy of March of Dimes (MOD) lie in voluntarism, collaboration with scientists and political activism. He also said that MOD has been successful in bringing out many laws in the US to protect the mother and child. He appreciated the involvement of Rotarians in this project and encouraged them to plan and execute strategies at the legislative level as they have done in the Pulse Polio program.

Rotarian T. Prasanna (President - Rotary Club of Madras Metro) in his speech extended his club's whole hearted support for the cause. He thanked Dr. Suresh, fellow Rotarian for inducting the club into this long term project. He said that his members would work primarily to create awareness in the community regarding birth defects. He hoped that this project would gain momentum for posterity and the future generation be born with less birth defects. Dr. Suchitra Ravishankar (Associate Clinical Dysmorphologist) proposed vote of thanks at the end.

Introduction:

Birth defects registry of India (BDRI) was established in 2001 with an objective of estimating the birth prevalence of congenital malformations in India. BDRI is a hospital-based surveillance programme, which collects data on births / birth defects from hospitals from defined geographic areas. BDRI relies on voluntary reporting of data. (Passive surveillance) The validity of the data is checked by the dysmorphologist and stored in a database. The final diagnosis assigned is then coded according to ICD10 published by the 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. This was the third consecutive annual report of the registry where the data collected from Chennai, Erode & Salem birth defects registries were presented.

This report presents the prevalence of congenital malformations noted among the 41,689 births which were monitored by the above mentioned three registries. The following tables present the system specific and anomaly specific prevalence.

Diagnostic Grouping	Number of cases	Prevalence / 10,000
A. Congenital Anomalies of the Central Nervous System (Q00 – Q07)	170	407
A01 Anencephaly (Q00.0) (Incl. Acrania)	52	124
A02 Encephalocele (Q01.0 – Q01.9) (Incl. Frontal & Occipital Encephalocele/ Meningocele)	19	45
A03 Microcephaly (Q02)	7	16
A04 Congenital Hydrocephalus without Spina bifida (Q03.0 – Q03.9) (Incl. Dandy – Walker malformation, Ventriculomegaly)	23	55
A05 Spina bifida without anencephaly (Q05.0 – Q05.9) (Incl. Meningocele, Meningomyelocele, Myelocele, Rachischisis, excluding Spina bifida occulta)	61	146
A06 Holoprosencephaly (Q04.2)	3	0.7
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.)	23	55

Diagnostic Grouping	Number of cases	Prevalence / 10,000
B. Congenital Anomalies of Eye, Ear, Face & Neck (Q10 – Q18)	15	35
B01 Anophthalmos / Microphthalmos / Macrophthalmos (Q11.0 – Q11.9)	2	0.4
B02 Coloboma Iris (Q13.0)	2	0.4
B03 Low set ears (Q17.4)	5	12
B04 All other congenital anomalies of Eye, Ear, Face & Neck (Q10 – Q18) (Incl. Imperforate auditory meatus)	11	26

Diagnostic Grouping	Number of cases	Prevalence / 10,000
D. Congenital anomalies of the Respiratory system (Q30 – Q34)	8	19
D01 Choanal atresia (Q30.0)	1	0.2
D02 Laryngomalacia (Q31.4)	1	0.2
D03 Laryngeal atresia (Q31.8)	1	0.2
D04 Hypoplastic lung (Q33.6)	5	12

Diagnostic Grouping	Number of cases	Prevalence / 10,000
C. Congenital Anomalies of the Circulatory System (Q20 – Q28)	75	180
C01 Common Truncus / Persistent Truncus arteriosus (Q20.0)	4	0.9
C02 Double outlet right ventricle (Q20.1)	3	0.7
C03 Transposed Great vessels (Q20.3)	3	0.7
C04 Single Ventricle (Q20.4)	1	0.2
C05 Ventricular Septal Defect (Q21.0)	20	47
C06 Atrial Septal Defect / Patent or persistent foramen ovale (Q21.1)	11	26
C07 Atrioventricular septal defect / Endocardial Cushion Defect / Ostium primum (Q21.2)	3	0.7
C08 Tetrology of Fallot (Q21.3)	3	0.7
C09 Pentalogy of Fallot (Q21.8)	1	0.2
C10 Pulmonary valve Atresia (Q22.0)	2	0.4
C11 Pulmonary valve Stenosis (Q22.1)	2	0.4
C12 Tricuspid Atresia (Q22.4)	3	0. 7
C13 Ebstein's anomaly (Q22.5)	1	0.2
C14 Hypoplastic right heart syndrome (Q22.6)	1	0.2
C15 Bicuspid aortic valve (Q23.1)	1	0.2
C16 Hypoplastic left heart syndrome (Q23.4)	6	14
C17 Patent ductus arteriosus (Q25.0)	3	0.7
C18 Hypoplasia of arch of Aorta (Q25.4)	2	0.4
C19 Hypoplasia of pulmonary artery (Q25.7)	2	0.4
C20 Persistent left superior vena cava (Q26.1)	1	0.2
C21 Single umbilical artery (Q27.0)	11	26

Diagnostic Grouping	Number of cases	Prevalence / 10,000
E. Congenital anomalies of the Gastrointestinal tract (Q35 – Q45)	74	177
E01 Cleft palate (Q35.0 – Q35.9)	9	21
E02 Cleft lip (Q36.0 – Q36.9)	8	19
E03 Cleft palate & cleft lip (Q37.0 – Q37.9)	28	67
E04 High arched palate (Q38.5)	1	0.2
E05 Other congenital malformations of tongue and mouth (Q38.3, Q38.6)	1	0.2
E06 Atresia of oesophagus without fistula (Q39.0)	2	0.4
E07 Tracheo-oesophageal fistula with atresia (Q39.1)	4	0.9
E08 Tracheo-oesophageal fistula without atresia (Q39.2)	6	14
E09 Absence, atresia and stenosis of small intestine (Q41.0 – Q41.9)	5	12
E10 Imperforate anus (Q42.3)	5	12
E11 Other Congenital malformations of intestines (Q43.0 - Q43.9)	5	12
E12 Agenesis of gall bladder (Q44.0)	2	0.4

Diagnostic Grouping	Number of cases	Prevalence / 10,000
F. Congenital Anomalies of the Genital and Urinary Systems (Q50 – Q64)	78	187
F01 Congenital malformation female genital organs (Q50.0 – Q52.9)	3	0.7
F02 Undescended testis (Q53.0 – Q53.9)	3	0.7
F03 Hypospadias (Q54.0 – Q54.9)	10	23
F04 Other congenital malformations of male genital organs (Q55.0 – Q55.9)	2	0.4
F05 Indeterminate sex (Q56.4)	10	23
F06 Renal agenesis (Q60.0 – Q60.6)	22	52
F07 Cystic kidney disease (Q61.0 – Q61.9) (Incl. Infantile or Adult polycystic kidney and Multicystic dysplasia)	10	23
F08 Congenital hydronephrosis (Q62.0)	8	19
F09 Pelviureteric junction obstruction	2	0.4
F10 Other congenital obstructive defects of renal pelvis & Ureter (Q62.3)	1	0.2
F11 Other congenital malformations of kidney (Q63.0 - Q63.9) (Incl. Fused / Horseshoe kidney)	6	14
F12 Congenital posterior urethral valve (Q64.2)	6	14
F13 Other congenital malformations of bladder & urethra (Q64.3)	5	12

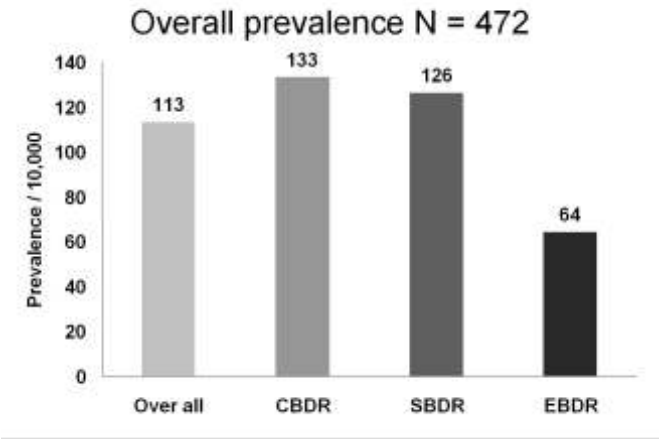
Diagnostic Grouping	Number of cases	Prevalence / 10,000
I. Multisystem Anomalies / Syndromes	7	16
I01 Pierre Robin syndrome (Q87.0)	2	0.4
I02 Meckel Gruber Syndrome (Q61.9)	1	0.2
I03 Other Syndromes (Q87.9)	4	0.9

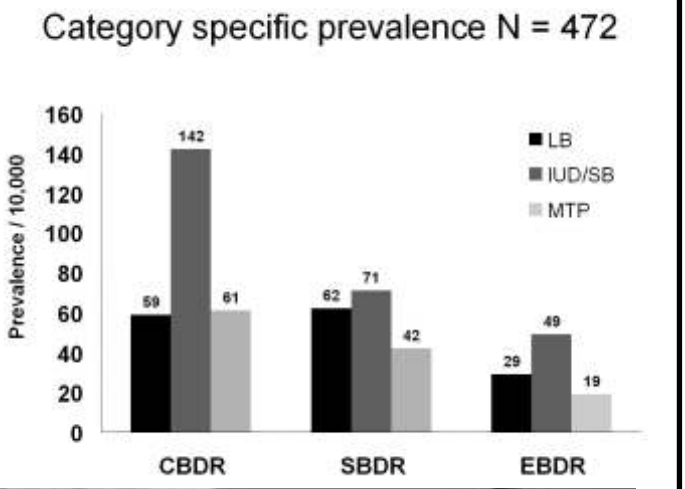
Diagnostic Grouping	Number of cases	Prevalence / 10,000
J. Chromosomal Anomalies (Q90)	14	33
J01 Down's Syndrome (Q90.0 – Q90.9)	10	23
J02 Edwards' Syndrome & Patau's syndrome (Q91.0 – Q91.9)	2	0.4
J03 Turner's Syndrome (Q96.0 – Q96.9)	2	0.4

Diagnostic Grouping	Number of cases	Prevalence / 10,000
G. Congenital Anomalies of the Musculoskeletal System (Q65 – Q79)	156	374
G01 Congenital dislocation of hip (Q65.0)	1	0.2
G02 Talipes equinovarus (Q66.0)	54	129
G03 Other Congenital malformations of feet (Q66.1- Q66.9) (Incl. Rocker bottom foot)	13	31
G04 Congenital Musculoskeletal deformities of head, face, spine & chest (Q67.0 – Q67.9) Incl. Dysmorphic face (Q67.0)	32	76
G05 Congenital deformities of knee (Q68.2) Genu recurvatum	4	0.9
G06 Polydactyly (Q69.0 – Q69.9)	11	26
G07 Syndactyly and polysyndactyly (Q70.0 – Q70.9)	5	12
G08 Upper limbs - reduction defects / shortening (Q71.0 – Q71.9)	6	14
G09 Lower limbs - reduction defects / shortening (Q72.0- Q72.9)	1	0.2
G10 Unspecified limbs - reduction defects / shortening (Q73.0 – Q73.8)	3	0.7
G11 Arthrogryposis (Q74.3)	3	0.7
G12 Other congenital malformations of limbs (Q74.8 & Q74.9)	14	33
G13 Hypertelorism (Q75.2)	1	0.2
G14 Other congenital malformations of skull & face bones (Q75.0– 75.9)	3	0.7
G15 Spina bifida occulta (Q76.0)	2	0.4
G16 Other congenital malformations of bony thorax (Q76.8)	1	0.2
G17 Osteochondrodysplasia with defects of growth of tubular bones & spine (Q77.0 – Q77.9)	5	12
G18 Osteogenesis imperfecta (Q78.0)	3	0.7
G19 Diaphragmatic Hernia (Q79.0)	11	26
G20 Absence / Eventration of diaphragm (Q79.1)	1	0.2
G21 Exomphalos / Omphalocele (Q79.2)	17	40
G22 Gastroschisis (Q79.3)	2	0.4
G23 Other congenital malformations of abdominal wall (Q79.8, Q79.9) (Incl. Limb body wall complex)	5	12

Diagnostic Grouping	Number of cases	Prevalence / 10,000
H. Other Congenital Anomalies (Q80 – Q86 & Q89)	9	21
H01 Single palmar crease (Q82.8)	2	0.4
H02 Absent / Hypolastic spleen (Q89.0)	1	0.2
H03 All other congenital malformations not elsewhere classified (Q89.9)	7	16

COMPARITVE PREVALENCE OF BIRTH DEFECTS IN CHENNAI, ERODE AND SALEM





Nodal Centre at West Godavari, Andhra Pradesh, inaugurated:

Dr. Ch. V. Narayana Rao, Consultant Sonologist, Shilpa Scan Centre, Bhimavaram , has taken good efforts to motivate his colleagues in West Godavari district to join the mission of BDRI. The dignitaries present at the inaugural function include, Dr.Ch. Satyanarayana Murthy (M.L.A, Palakol Constituency), Shri. Sanjay Jajoo (District Collector), Dr. Raghavulu (President, Palakol I.M.A),Dr. Krishnasimha Raju, (President, Bhimavaram I.M.A) and the others from the medical fraternity of the district. The collector emphasized the need for the medical professionals from both Government and private sector to extend their full co operation for this project. Dr. S. Suresh spoke on the need and scope of birth defects registries in India. This was followed by Dr.G. Thangavel, who explained the methodology of operation of BDRI to the proposed members. BDRI hopes to receive the maximum participation of members in West Godavari District and derive beneficial data on birth defects in the years to come.

An appeal

Dear Members

Hope all of you are aware of the existence of the "Support Group for Mucopolysaccharidoses (MPS)" functioning at our premises. It was inaugurated in August last year. A Multi speciality MPS Clinic was arranged under one roof in last December to do a preliminary examination of the children who were diagnosed to have different types of MPS. A group of medical specialists, physiotherapist and yoga therapists examined the children and gave their reports. We meet the parents enrolled once in a month and discuss various issues concerning the mode of operation of the support group, creation of awareness about MPS in our society through press and audio-visual media and fund raising etc.

Since there is no immediate cure for these disorders through medicines, we have determined to provide the best possible supportive care to the affected children through the support group, Hence if you come across a case of MPS (with / without confirmation) in your practice, kindly ensure that child is registered in the support group. There is no registration fee for enrolment. Kindly extend your cooperation for a genuine cause.

Kindly contact us at : **Fetal Care Research Foundation,** No : 203, Avvai Shanmugam Salai, Royapettah, Chennai - 600014.
Ph: 044 - 28116965 E - Mail : fcrf@mediscansystems.org Website : www.mediscansystems.org

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