BIRTH DEFECTS REGISTRY OF INDIA

(Birth Defects Registry of India, Chennai)
A Unit of Fetal Care Research Foundation
197, Dr, Natesan road, Mylapore, Chennai- 600004. INDIA.
Ph : 91-44–2466 3150, 2466 0409 Fax: 91- 44-2498 8226
e-mail: bdri@mediscan.org.in

Introduction

The Birth Defects Registry of India (BDRI) is a unit of Fetal Care Research Foundation (FCRF), a non-profitable charity trust. The Central Office of the Registry Functions at the address mentioned above. BDRI will function as an umbrella organization, which will collate information from multiple regional registries. The regional registries may be started in a well-defined geographic location like a city / parts of a city like North, East, South or West / Town / District / Taluk. The primary aim of the registry is to find out the baseline frequency of various birth defects in India and the pattern of distribution. Over a period of time, information on recurrence rates of various anomalies will also be computed. The ultimate goal of the registry is to bring about prevention of birth defects, reduction in the incidence of birth defects and creating support groups for various congenital disorders. This will help in counseling parents and to plan the necessary infrastructure required for management of correctable disorders.

Who should join the registry?

- Obstetricians
- Neonatologists
- Pediatricians

All birth defects registries commissioned at various regions of the country will be governed by the rules and regulations of the BDRI and will follow the Birth Defects Charter annexed (Annexure –A).

(Annexure – A)

RULES AND REGULATIONS OF THE BIRTH DEFECTS REGISTRY OF INDIA

Any hospital / maternity center from both government and private sector, with an interest and commitment to the above mentioned goal could become a member.

Registration for membership:

Any qualified medical doctor from the above fraternity can register and become a member by accessing the BDRI website using the link www.fcrf.org.in.

Member once registered will be assigned a specific code/identity and inducted into the registry Members of the BDRI will be classified as a Nodal member or Participating member. BDRI assigns the nodal member at its own discretion for a region. The Nodal member hospital is the coordinating body of the participating member hospitals in its respective region.

Role of BDRI Member:

Member hospitals are expected to submit data on total deliveries and the number of birth defects that may happen in their respective hospital/nursing home month wise in prescribed forms (FORM- A & FORM- B) provided by BDRI. **Members may opt to report data online or as hard copies and send by post/courier.** If a member chooses to report data online he or she may do so by accessing the data base through their special password assigned by BDRI. Hard copies with monthly data may be collected and sent to the central registry once in two months for convenience.

Role of Nodal member: If members in regional registry are operating under a Nodal member, the nodal member is responsible for collection of month wise data on births & birth defects from its own center and member hospitals.

Collection may be done once in two months for operational convenience.

Nodal member:

- The nodal member is a person who is willing to Champion the cause of the registry in his / her region

- may assign a qualified medical professional to furnish their hospital data to the registry.

- may organize BDRI meetings periodically in their respective region with the participating members to share knowledge on the management of various birth defects.

- is responsible for all the expenditures incurred like stationary, personnel etc for the functioning of the registry in their respective regions.

- may enroll new members at their own discretion. However information regarding new recruitments needs to be intimated to BDRI within a month. Similarly, if a member wishes to withdraw membership, BDRI office should be intimated a month in advance.

The data collected at the nodal centers may be sent to the central office of BDRI once in 2 months.

Analysis of the data will be done on yearly basis by **interfacing with the government authorities and** will be communicated to all members through the official News Letter / World Wide Web.

BDRI may be contacted for help in case of diagnostic difficulties. However if any tests are required for the fetus, child or couple, the cost has to be borne by the parents.

- BDRI will periodically publish the data for dissemination of information. Nodal centers and participating members may request for the data pertaining to their registry. Individual member can publish their own data after due notification to the BDRI.

- BDRI publishes newsletters on quarterly basis in the months of January, April, July and October every year. Articles of interest and other related matters are welcome form member hospitals for publication.

- Members are expected to involve in all the activities (academic, public education, fund raising etc) of the Central Registry actively and contribute wholeheartedly to the growth of the registry.