MALTA CONGENITAL ANOMALIES REGISTRY

AIMS OF REGISTRY

- To collect data about all fetal deaths and infants with a diagnosis of congenital anomalies on the islands of Malta and Gozo
- To keep a register of all cases of congenital anomalies diagnosed until one year of age
- To provide data which may be required for epidemiological and research studies
- To detect any changes in occurrence of congenital anomalies
- To issue regular reports and provide physicians and the general public with information they may need, always respecting strict confidentiality.

BACKGROUND

Data on congenital anomalies diagnosed at birth at St. Luke's Hospital (Malta) was originally collected through the University of Malta between 1985 and 1996. The register became a member of EUROCAT (European Surveillance of Congenital Anomalies) in 1986. Funding for this project by the University of Malta ran into difficulties in 1995 and subsequently the Department of Health Information and Research (DHIR) started co-ordinating all previous efforts of recording congenital anomalies. A population based Malta Congenital Anomalies Register was established by the DHIR as of January 1997. This register now covers births from all hospitals on the Maltese Islands and includes all cases suspected or diagnosed with a congenital anomaly until one year of age. This register actively collaborates with EUROCAT Joint Action and closely follows EUROCAT guidelines. It is also a member of the ICBDSR (International Clearinghouse of Birth Defects Surveillance and Research).

COVERAGE

The register is population based and includes all births on the islands of Malta and Gozo which amount to around 4000 births per year. The small size and population of the islands (area: 316 km2; population: 404,962); the well-defined boundaries, absence of significant ethnic minority groups and illegality of termination of pregnancy make the islands ideal for epidemiological studies.

DATA COLLECTION AND SOURCES OF INFORMATION

Congenital Anomalies, for the purposes of the register, are defined as '**structural, functional, metabolic, behavioural and hereditary defects present at birth**'.

Data collection occurs on both a passive and active basis. On a passive basis, paediatricians and health care professionals are asked to report any newly diagnosed cases of congenital anomalies. On an active basis, members of the staff of the DHIR visit hospital obstetric, paediatric and echocardiography units to collect data

directly and review patient notes.

All hospitals are involved in data capture and include: Mater Dei Hospital (MDH), Gozo General Hospital (GGH), St. James Hospital - Sliema and Zabbar.

Several sources of data are used to ensure as complete a coverage as possible. Present sources of data from include: Doctors' notifications, notifications from all delivery units, obstetric wards, neonatal and paediatric intensive care units, Echocardiography Lab., Genetics Clinic, National Obstetrics Information System, Hospital Activity Analysis Register, Mortality Register, Pathology Autopsy reports, and Hypothyroid screening programmes.

The registry keeps named records in order to:

i) link reports arriving from several sources, and so avoid duplicate registration;

ii) allow the follow up of cases to confirm, update the diagnosis and to study the outcome of malformed children; and

iii) trace the cases in order to conduct prospective or retrospective epidemiological studies.

Patient Hospital files are reviewed whenever possible to validate and ensure accuracy of registrations. Strict confidentiality is respected at all times.