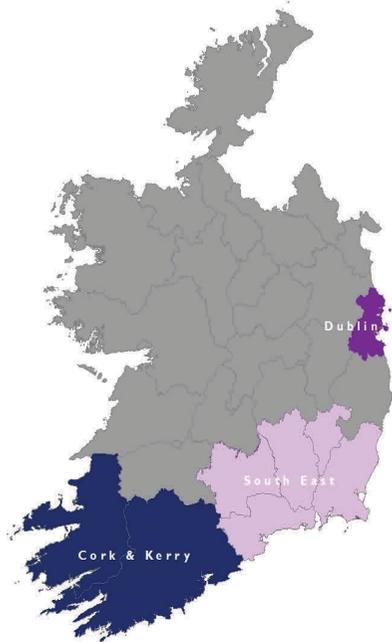


Location of all three HSE Congenital Anomaly Registers in Ireland



Contact Us:

Cork & Kerry Congenital Anomaly Register

Dr. Mary O'Mahony / Ms. Maria Ryan
Department of Public Health,
HSE South (Cork & Kerry), Floor 2, Block 8, St. Finbarrs
Hospital, Douglas Road, Cork, Ireland.
Tel: + 353 21 4927601
Fax : + 353 21 4923257
E-mail: maryt.omahony@hse.ie / Maria.Ryan1@hse.ie

Dublin Congenital Anomaly Register

Dr. Bob McDonnell / Ms. Virginia Delaney,
HSE Registry of Congenital Anomalies - East,
Health Intelligence Unit, Health & Wellbeing,
Health Service Executive,
Dr Steeven's Hospital, Dublin 8, Ireland.
Tel: +353 1 6352750/1
Email: bob.mcdonnell@hse.ie / virginia.delaney@hse.ie

South East Congenital Anomaly Register

Dr. Catherine Lynch / Ms. Johanna Costigan
Department of Public Health
Health Service Executive - South
Lacken, Kilkenny, Ireland
Tel: +353 56 7784100

Email: Catherine.Lynch@hse.ie
johanna.costigan@hse.ie

Web:

<http://www.eurocat-network.eu/>
<http://www.hse.ie/congenitalanomalyregistersireland>



Congenital Anomaly Registers in Ireland



Cork & Kerry Congenital
Anomaly Register

Dublin Congenital Anomaly
Register

South East Congenital
Anomaly Register

Congenital Anomaly Registers Ireland

The birth of a healthy baby is every parents wish. However, some babies are born with anomalies or abnormalities such as cleft lip, spina bifida or Down's syndrome. These are referred to as congenital anomalies.

Why information is collected about babies with congenital anomalies.

The HSE Congenital Anomaly Registers collect information:

- To learn more about congenital anomalies and help research into their causes, treatment and prevention
- To provide early warning of potential harmful exposures that may contribute to anomalies during pregnancy
- To examine the survival and health of babies born with anomalies
- To look at trends and the numbers of babies born with a congenital anomaly in our region
- To help plan and develop our health service for these conditions
- To participate and contribute to the European network of Congenital Anomalies

HSE Congenital Anomaly Registers

There are three active regional congenital anomaly registers in the Republic of Ireland; all are

members of EUROCAT, the European network of congenital anomaly registers. Together the registers cover 60% of all births in Ireland. Each register is led by a medical doctor, a HSE Specialist in Public Health Medicine. Data is collected by a research nurse. All are permanent HSE staff working in departments of public health.

What information is collected?

Information held by the register includes:

- A detailed description of the anomaly
- Details about mother and baby such as age and weight of mother, date of delivery, medications taken and smoking status during pregnancy
- The names and addresses of mother and baby **are not** stored on the register database

Who sees the information?

There are very strict regulations controlling access to your personal information and all HSE staff are bound by confidentiality. This information is only accessible to members of HSE staff who treat you and your baby and to those who work directly with the HSE congenital anomaly register.

Only anonymous data from the Irish registries is recorded on local registries and is sent to EUROCAT for European surveillance of congenital anomalies.

Information that is approved for use by researchers or published in reports does not contain anything to identify either mother or baby, such as names and addresses.

Can I see the records on the Register?

Yes — you are entitled to request a copy of the information held on you or your baby. To do this contact the register in your area by telephone or e-mail.

How is information collected?

The HSE register nurse examines birth records and hospital medical records in each of the hospitals covered by her registry region to identify babies who have been born with an anomaly. The information collected is stored electronically on a secure computer and maintained by the registry nurse in HSE Departments of Public Health.

Will the database be secure and confidential?

Yes, all information collected by HSE Congenital Anomaly nurses about you and your baby is confidential. It is held in a responsible way that protects your rights and your privacy. The three Congenital Anomaly Registers are registered with the Data Protection Commissioner and are governed according to the provisions of the Data Protection Act 1988 (Amended 2003).

Will information be available from the register?

Information is analysed on an ongoing basis and regular reports and publications are publicly available on the HSE.ie website <http://www.hse.ie/congenitalanomalyregistersireland>. All EUROCAT publications on congenital anomalies are listed on the EUROCAT website <http://www.eurocat-network.eu/>.