

More information

You can find out more about the North Thames (West) Congenital Malformation Register by contacting the registry at:

**North Thames Perinatal Public Health Unit
Kennedy Galton Centre
Northwick Park and St Mark's Hospital NHS
Trust
Watford Road
Harrow
HA1 3UJ**

Tel: 020 8869 3527

List of hospitals contributing to the register:

Barnet
Bedford
Central Middlesex
Chelsea and Westminster
Ealing
Edgware
Hemel Hempstead
Hillingdon
Lister
Luton and Dunstable
Northwick Park
Queen Charlotte's and Chelsea
Queen Elizabeth II
St Albans
St Marts
Watford
West Middlesex

**Bedford Hospital Maternity Services
Bedford Hospital Cygnet Wing
Kempston Road
Bedford
MK42 9DJ**

01234 355 122

www.bedfordhospital.nhs.uk

Bedford Hospital **NHS**
NHS Trust

Bedford Hospital **NHS**
NHS Trust

Maternity Monitoring Congenital Anomalies



An information leaflet explaining how and why information is collected by the North Thames (West) Congenital Malformation Register.

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every patient matters

Every pregnant woman hopes that her baby will be healthy, and most babies are. However some babies are born with abnormalities such as a cleft palate, spina bifida or Down's syndrome. These are sometimes referred to as congenital anomalies or congenital malformations.

Some congenital anomalies are detected during pregnancy, some are discovered at birth and some become obvious only as the baby grows older.

The North Thames (West) Congenital Malformation Register collects information about babies born with suspected or confirmed congenital anomalies in north west London and the surrounding areas.

This information is collected and recorded to help advance the understanding of these abnormalities to help to improve and develop NHS services for the future.

What information is collected?

Information held on the register includes:

- Descriptions of each anomaly;
- Details and results of investigations carried out during pregnancy (for example, results of ultrasound scans);
- Details about the mother and baby including names, dates of birth and postcodes.

How is the information collected and stored?

A member of staff from the maternity unit will provide the information to the register. The information is collected on paper and is held electronically by the North Thames (West) Congenital Malformation Register which is based at Northwick Park Hospital. The database is stored on a secure computer that is not connected to the internet and can be accessed only by register staff.

Who will be able to see information stored about me and my baby?

Information about you and your baby will be treated as strictly confidential and is held securely in line with the Data Protection Act.

There are very strict regulations controlling access to information on the database; it will only be available to healthcare staff who are treating you or your baby, and those who work on the North Thames (West) Congenital Malformation Register.

Information is also sent to the National Congenital Anomaly Surveillance System which collects information for the whole country. When this happens, only the first three letters of the baby's name are sent.

Any information that is used by researchers or for reports **will not** contain names, dates of birth or anything else that could identify either yourself or your baby.

Can I see the records relating to me or my baby on the register?

Yes, you have the right to request a copy of the information held about you or your baby. To do this, please make your wishes known to a member of your healthcare team.

Does my name or my baby's name have to go on the register?

The register makes significant contributions to developments in healthcare and we are grateful to everyone who allows their details to be stored. However, if you do not wish for you or your baby to be included, your details can be removed at any time upon your request.

