

Consent For Genetic Examination

Information Guide

Genetic examination: Information for parents

If your baby has been found to have abnormalities on antenatal scan or has been born with one or more congenital abnormalities you may be asked to consider your baby having an external examination by a Clinical Geneticist (specialist genetics doctor) or genetic tests.

Many parents in this situation want to know

- Why has my baby had these problems?
- Is the problem genetic?
- What are the chances of this happening again in a future pregnancy?
- Are there any tests that I could be offered in a future pregnancy?

Examination of your baby by a Clinical Geneticist may help to answer these questions.

What does this involve?

Your baby will be transferred temporarily to the mortuary at Royal Manchester Children's Hospital.

A Clinical Geneticist will examine your baby **externally**.

This is not a post mortem examination. If your obstetrician feels a post mortem would be helpful you may be asked to give separate consent for examination by a pathologist.

The doctor will take measurements and look for physical differences that together might suggest a diagnosis.

If you consent, the Clinical Geneticist may take photographs to record any abnormalities. This is for the clinical record and photographs will be stored on a password-protected photographic database in the Department of Genetic Medicine. The photographs will normally be discussed with other clinical genetics doctors so that several opinions can be obtained.

Will the clinical geneticists do any other tests?

X-rays are often helpful and are essential in making an exact diagnosis if your baby has a suspected skeletal dysplasia (genetic bone disorder).

In some cases genetic analysis of tissue samples can help in reaching a diagnosis. There are two major types of genetic tests (which may not be possible in every case):

- **Chromosome tests:** This involves taking a small piece of tissue (usually a piece of the baby's umbilical cord or skin) for chromosome testing.
- **DNA tests:** This involves extracting DNA from a tissue sample. Often internal organ tissue is best for this and these tests might not be possible unless a post mortem examination is performed.

If the geneticist suspects a particular gene disorder a DNA sample may be sent for gene testing.

Sometimes an exact diagnosis is not possible but it may be helpful to store DNA in case a diagnosis is reached or tests are possible in the future.

In some cases the availability of early prenatal diagnosis in a future pregnancy may depend on having DNA stored.

What will happen afterward?

The Clinical Geneticist will not contact you directly, but will write to your obstetrician explaining the findings.

Your obstetrician will then be able to discuss the findings with you. If appropriate, they may, when you feel ready, refer you to the clinical genetics clinic to discuss the results further.

For additional information or support

If you need advice about any aspect of genetic examination of a baby, you are welcome to contact the Department of Genetics Medicine where you could speak to a Clinical Geneticist (doctor) or a Genetic Counsellor (co-worker).

The contact details are displayed below.

Suggestions, concerns and complaints

If you wish to make a comment, have a concern or want to complain, it is best in the first instance to speak to the manager of the ward or department involved.

The Trust has a Patient Advice and Liaison Service (PALS) who can be contacted on (0161) 276 8686 and via e-mail: pals@cmft.nhs.uk. They will help you if you have a concern, want advice or wish to make a comment or complaint.

Information leaflets about the service are readily available throughout the Trust. Please ask any member of staff for a copy.

For more information:

If you need more advice, you are welcome to contact:

Genetic Medicine

Sixth Floor
St Mary's Hospital
Oxford Road
Manchester
M13 9WL

Telephone: 0161 276 6506 (*Reception*)

Facsimile: 0161 276 6145

www.mangen.co.uk

Department staffed Monday – Friday 8.30am to 5.00pm

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio, British Sign Language video/DVD) or in another language.

No smoking policy

The NHS has the responsibility for the nation's health.

Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.

The Manchester Stop Smoking Service can be contacted on Tel: (0161) 205 5998 (www.stopsmokingmanchester.co.uk).

Translation and Interpretation Service

Do you have difficulty speaking or understanding English ?

আপনি কি ইংরেজীতে বুঝতে কিংবা বুঝাতে পেরেছেন ? (BENGALI)

क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ? (HINDI)

તમે ભાષા કારણે વાતચીત કરવામાં મુશ્કેલી આવે છે ? (GUJARATI)

ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਜਾਂ ਸਮਝਣ ਵਿਚ ਦਿੱਕਤ ਹੈ ? (PUNJABI)

Miyey ku adagtahay inaad ku hadasho Ingriisida aad sahamto (SOMALI)

هل لديك مشاكل في فهم اوالتكلم باللغة الانجليزية ؟ (ARABIC)

你有困難講英語或明白英語嗎？ (CANTONESE)

کیا آپ کو انگریزی سمجھنے اور سمجھانے میں دقت پیش آتی ہے؟ (URDU)

☎ Telephone 0161 276 6202 / 6342