

# Screening for Down's, Edwards' and Patau's Syndrome

This information should be read together with the NHS Screening Programmes booklet 'Screening tests for you and your baby' which is in your booking pack.

## **Combined screening during your dating scan: What will happen if I decide to have the test?**

When you arrive in the Fetal Medicine Unit, a member of the team will take a blood sample. The blood takes approximately 40 minutes to be processed. After this, you will go for your ultrasound scan appointment, which takes around 30 minutes. The sonographer (person performing the scan) will discuss the results with you and you will be given a printed report to keep in your maternity notes.

You should expect to be in the Fetal Medicine Unit around one to two hours. You do not need to have full bladder for the scan, but it can help the quality of images if you avoid going to the toilet just before the scan.

## **Are there any risks from this test to me or my baby?**

The scan and the blood test are safe and will not harm you or your baby.

## **How are the chances of Down's, Edwards' and Patau's syndromes calculated?**

The risk of Down's, Edwards' and Patau's syndrome is based upon a combination of:

- your age (and some other factors like your ethnicity, whether you smoke or not, whether you are diabetic)
- the measurement of nuchal translucency (NT) (Small space at the back of the baby's neck)
- the length of your baby and your baby's heart rate
- the level of two hormones (PAPP-A and free B-hCG) in your blood.

We use a 'risk cut-off' of one in 150 at term to identify babies that are considered as having a higher risk of Down's, Edwards' and Patau's syndrome. This means that if your combined test result indicates a risk of between one in two and one in 150, your baby is at increased risk of one or more of these conditions. If the results show a risk of one in 151 or more, this is

classified as a lower risk result, meaning that your baby is less likely to have one of these conditions.

### **What happens if I have a high risk result?**

If your screening result indicates a higher risk for your baby having Down's , Edwards' or Patau's syndrome, you will be offered the opportunity to discuss the options of whether you want to find out for certain if your baby is affected by any of these conditions, or not.

If you want to find out for certain, diagnostic testing such as Chorionic Villus Sampling (CVS) carried out at 11 to 14 weeks, or Amniocentesis carried out from 16 weeks onwards will be discussed.

These tests can give a clearer indication of whether or not your baby has Down's, Edwards' or Patau's syndromes. However these tests carry a risk of miscarriage of around one in 100 above the usual risk of miscarriage. If you have difficulty deciding what to do or would like further counselling, the fetal medicine midwives are available to discuss the options.

### **Attending your appointment**

Appointments for combined screening are in demand due to the limited period of time in which they can be performed. If the appointment you are sent is not convenient or if for any reason you are unable to keep it, please telephone 020 7188 8003 and let us know.

If you are late for your appointment, we may not be able to perform your scan or give you another appointment.

It is important that the sonographer is able to concentrate during the scan, so we ask that there are only one or two people in the room during the ultrasound examination. Taking pictures or films during the ultrasound is strictly forbidden.

Guy's and St Thomas' is a teaching hospital, and so we may wish to use images from your scan to help students learn. Please speak to the sonographer if you have any questions or concerns, or if you do not want images from your scan to be used in teaching.

### **Are there any alternatives to the combined test?**

There are other screening tests available, which can be carried out at different stages in your pregnancy.

### **Quadruple test (serum screening)**

If your pregnancy is too advanced (more than 14 weeks 1 day) for the combined test to be carried out, or we were unable to obtain nuchal translucency measurement for any reason, we will offer you another blood test. This is called the quadruple test. This test can be done between 14 weeks 2 days and 20 weeks 0 day of pregnancy.

If you have had a combined test you do not need the quadruple test in addition.

### **What if I decide not to have the combined test (decline screening)?**

The screening for Down's , Edwards' or Patau's syndromes is optional. If you decide not to have any screening, we will still offer you an ultrasound scan to date the pregnancy and check your baby's physical health and progress.

## Further information

You can get more information about screening from the following organisations:

### Antenatal Results and Choices

t: 020 7631 0281

w: [www.arc-uk.org](http://www.arc-uk.org)

### Fetal Medicine Foundation

t: 020 7034 3070

w: [www.fetalmedicine.com](http://www.fetalmedicine.com)

### NHS Screening Programmes

Antenatal and Newborn Screening Programmes

w: [www.screening.nhs.uk](http://www.screening.nhs.uk)

[www.nhs.uk](http://www.nhs.uk)

### National Institute for Health and Clinical Excellence

w: [www.nice.org.uk](http://www.nice.org.uk)

## Contact us

If you have any questions or concerns about the test, please contact the Fetal Medicine Unit on **020 7188 2321** and ask to speak to the **Fetal Medicine Midwives**.

The Fetal Medicine Unit is open between 9am and 5.00pm, Monday to Friday.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

### Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) e: [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

t: 020 7188 3514 (complaints) e: [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 e: [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

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