Screening tests for you and your baby
Be sure you understand the purpose of all the tests before you take them. Don’t be afraid to ask.

**Pre-conception**

- Commence folic acid

**Blood for haemoglobin, group, rhesus & antibodies, as early as possible, or as soon as a woman arrives for care, including labour**

**Blood for Sickle Cell & Thalassaemia**

**Blood for early Down’s syndrome test**

**Antenatal**

**Read pre-screening information as soon as possible**

- Dating scan
- Nuchal Translucency scan
- Detailed ultrasound anomaly scan

Using this booklet

- Screening for Sickle Cell and Thalassaemia in pregnancy
- Testing for Down’s Syndrome in pregnancy
- Testing for infections in pregnancy

**Contents**

- Your baby’s hearing screen
- Newborn blood spot screening for your baby
- Notes

**Screening Timeline**
Blood for syphilis, Hepatitis B, HIV & Rubella immunity as early as possible, or as soon as a woman arrives for care, including labour.

Blood for later Down's syndrome test

Repeat haemoglobin & antibodies

Physical Examination by 72 hours

Physical Examination by 8 weeks

Read & discuss newborn screening information

Newborn Blood spot

Newborn Hearing Screen

Optimum times for testing
Using this booklet

We are pleased to be able to send you this information booklet. The booklet is about the screening tests you will be offered in pregnancy and screening for your baby in the first few weeks after birth.

It is important you understand the purpose and possible results of the screening tests before you make your decision. To help you the UK National Screening Committee* has written this booklet, explaining the screening tests in detail.

We realise you are given a lot of information in pregnancy but please read this booklet as it will help prepare you for discussions with your midwife or doctor about the screening tests, so you can ask the questions that are important to you. It will be helpful if you have the booklet with you when you see them.

As you can see from the screening timeline diagram on the inside front cover, some of the tests need to take place early in pregnancy so we recommend reading the booklet as soon as possible.

Towards the end of your pregnancy your midwife will discuss with you the screening tests recommended for newborn babies. We advise you to look at the booklet again at this stage.

We hope you find this booklet useful.

For more information on screening tests in pregnancy and for your baby please talk to your midwife, doctor or health visitor. You can also visit the following websites:

• For NSC antenatal and newborn screening programmes; www.screening.nhs.uk/lan
• For Antenatal Results and Choices charity; www.arc-uk.org
• For a directory of personal experiences; www.dipex.org/antenatalscreening
• For Contact a Family charity; www.cafamily.org.uk

* The UK National Screening Committee advises the Health Departments of the four UK countries on all aspects of screening
Screening for sickle cell and thalassaemia in early pregnancy
In the first few weeks of your pregnancy, we will offer you a blood test for sickle cell and thalassaemia. This leaflet describes the screening process. It explains why we offer the test and helps you decide whether to accept it.

What are sickle cell and thalassaemia disorders?

Sickle cell disorder and thalassaemia major are serious, inherited blood disorders. They affect haemoglobin, a part of the blood that carries oxygen around the body. People who have these conditions will need specialist care throughout their lives.

Sickle cell disorders

People with sickle cell disorders:
- can have attacks of very severe pain
- can get serious, life-threatening infections
- are usually anaemic (which means that their bodies have difficulty carrying oxygen), and
- need medicines and injections when they are children and throughout the rest of their lives to prevent infections.

Thalassaemia major

People with thalassaemia major:
- are very anaemic (their bodies have difficulty carrying oxygen)
- need blood transfusions every four to six weeks, and
- need injections and medicines throughout their lives.

There are also other, less common, haemoglobin disorders. Many of these are not as serious.
How are they passed on?
Sickle cell and thalassaemia are inherited disorders that are passed on from parents to children through unusual haemoglobin genes.

People only have these disorders if they inherit two unusual haemoglobin genes – one from their mother, and one from their father. People who inherit just one unusual gene are known as 'carriers'. (Some people call this having a 'trait'.)

Carriers are healthy and do not have the disorders.

But if a carrier has a baby with someone else who is also a carrier (or who has one of the disorders), there is a chance that their baby could inherit a disorder.

Who can be a carrier?
Anyone can be a healthy carrier. But you are more likely to carry the unusual genes if your ancestors came from places where malaria has been common. This is because being a carrier can help to protect people against malaria.

This means you are more likely to be a carrier if your ancestors came from the Mediterranean (for example Cyprus, Italy, Portugal, Spain), Africa, the Caribbean, the Middle East, India, Pakistan, South America or south and south-east Asia.

What tests are involved?
Screening involves a simple blood test. Ideally the best time to have the test is before you are 10 weeks pregnant.

All pregnant women are offered a blood test for thalassaemia. But you will not always be offered a blood test for sickle cell. You may be given a questionnaire to find out where your family – and the family of your baby's father – come from. If this shows you are at low risk, you may not be offered the blood test for sickle cell. But you can always ask for the test if you want it.
Why should I be tested?
The test gives important information for your baby’s health

- if the blood test shows that you are a carrier, we will invite your baby’s father for a test. If he is also a carrier, your baby has a chance of inheriting a disorder. (The diagram on page 3 shows the different chances for your baby. These include inheriting the disorder, being a carrier or not being affected.)

Finding this out early in your pregnancy gives you the chance to talk to a counsellor and find out more about the disorders and the care available. If you want to, you can have another test to confirm whether your baby has one of the disorders. (See 'Is there a further test?' on page 10).

The test can benefit you and your family

- If the test shows that you are a carrier, there is a chance that other members of your family could be carriers too. You may want to encourage them to ask for a test, especially if they are planning to have a baby themselves.

- Although people who carry sickle cell are healthy, they can experience some problems in rare situations where their bodies might not get enough oxygen (for example, when having an anaesthetic or during deep-sea diving). Knowing that you carry sickle cell can help you manage these situations.

However, people who carry thalassaemia or other unusual haemoglobin genes do not experience these problems.

For all of these reasons, we strongly recommend that you have screening. However, you can choose not to be tested, and we will respect your choice at all times.

Are there any risks?
Screening is a simple blood test, with almost no risk to you or your baby.

How will I get my results?
The person doing the test will discuss the arrangements for providing your results.

What will the results tell me?
The most likely result is that you are not a carrier. Your pregnancy should continue as normal.

If the result shows that you are a carrier for sickle cell, thalassaemia or another haemoglobin disorder, we will offer you counselling to talk about what this could mean for you, your baby and your family. We will also offer your baby’s father a test to find out whether he is a carrier.

In very rare cases, the test may show that you have a haemoglobin disorder without knowing it. A health professional (for example, a nurse, doctor or midwife) will discuss your options with you, including the care you will need while you are pregnant.

Although the test is between 95% and 99% accurate, in a small number of cases the result may be unclear. If this happens, we will usually offer you another test.
Why should my baby’s father have a test?

Babies can only inherit the disorders if both parents carry the unusual gene. So, if you are a carrier, it is important to find out whether the baby’s father is also a carrier.

If he is not available or does not want to have a test, we may offer another test to find out whether your baby has sickle cell or thalassaemia. (See ‘Is there a further test?’ on page 10).

What if my baby’s father is also a carrier?

If you and the baby’s father both carry the gene for sickle cell, thalassaemia or another haemoglobin disorder, for each baby you have there is:

- a 25% (one in four) chance that your baby will not be affected (that is, it will not have or carry a disorder)
- a 50% (two in four) chance that your baby will be a carrier, and
- a 25% (one in four) chance that your baby will have a disorder.

This is shown in the diagram below.

We will offer you counselling to discuss what this means for your family and what choices you want to make. If you want, you can choose to have another test to find out if your baby has sickle cell or thalassaemia or another haemoglobin disorder (see ‘Is there a further test?’ on page 10).