## what to do next?

If you want to know your sickle cell status you can ask your GP for a blood test. In some parts of the country there are also local sickle cell centres that can arrange a blood test for you.

You may have been screened for sickle cell disease. Screening is offered .

- To all newborn babies as part of the newborn bloodspot (heelprick test) when your baby is five days old. The key reason for offering newborn screening for sickle cell disease is because babies with sickle cell disease are vulnerable to serious infections. By identifying babies early in life , they can be prescribed penicillin and be referred for specialist care, so that they stay healthy.

Newborn screening also detects babies who have the trait (also known as a carrier) for sickle cell disease.

- To all pregnant women early in pregnancy (ideally by ten weeks) . Antenatal screening identifies parents to be who have the trait (also known as a carrier). If the mother is identified with the trait, the baby's father is offered a screening test.

SICKLE CELL SOCIETY

If you would like to know more about sickle cell disorder or the work of the Sickle Cell Society please contact.

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The evidence base for this leaflet is available on request and on our website.

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SICKLE CELL SOCIETY

# Sickle Cell Disorder & Sickle Cell Trait

**www.sicklecellsociety.org**

# did you know?

1. SCD is inherited from both parents; sickle cell trait is inherited from one parent.
2. SCD mostly, but not exclusively affects people from African and Caribbean backgrounds
3. 1 in 76 babies born in the UK carry sickle cell trait.
4. Approximately 15,000 people in the UK have sickle cell disorder.
5. Approximately 350 babies with SCD are born in the UK every year.
6. A simple blood test will tell whether you have sickle cell trait or the disorder
7. Children with SCD are at increased risk for stroke, the risk is highest between the ages of 2 and 16.
8. Episodes of pain may occur in sickle cell disorder and are generally referred to as a crisis

# sickle cell disorder

Sickle cell is a disorder of the haemoglobin in the red blood cells. Haemoglobin is the substance in red blood cells that is responsible for the colour of the cell and for carrying oxygen around the body.

People with sickle cell disorder are born with the condition, it is not contagious. It can only be inherited from both parents each having passed on the gene for sickle cell.

The main symptoms of sickle cell disorder are anaemia and episodes of severe pain. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then stick together, causing blockages in the small blood vessels.

These painful episodes are referred to as Sickle Cell crisis. They are treated with strong painkillers such as morphine to control the pain.

People with sickle cell are at risk of complications stroke, acute chest syndrome, blindness, bone damage and priapism (a persistent, painful erection of the penis).

Over time people with sickle cell can experience damage to organs such as the liver, kidney, lungs, heart and spleen. Death can also result from complications of the disorder. Treatment of sickle cell mostly focuses on preventing and treating complications.

The only possible cure for the disorder is bone marrow transplant but this is only possible for a limited number of affected individuals who have a suitable donor. A medicine called Hydroxyurea, can significantly reduce the number of painful crises.

# sickle cell trait

You are born with sickle cell trait. It is inherited when only one of your parents has passed on the sickle gene, and will never develop into sickle cell disorder.

You do not have symptoms from sickle cell trait, so it is a good idea to have a blood test to see if you have sickle cell trait.

If you have the trait, the majority of red cells in the blood are normal round shaped cells. Some sickle shaped cells may be present under certain conditions.

Sickle cell trait is found in 1 in 4 West Africans and 1 in 10 Afro-Caribbeans, and is also found in people who originate from the Mediterranean, Asia and the Middle East. It is less common in white Europeans.

Most people who have sickle cell trait are healthy. However, anaesthetics can cause problems. If you have sickle cell trait Always notify your dentist or doctor before treatment commences to be on the safe side.

There is a small chance that you may experience pain at high altitudes (generally above 10,000 feet), including long-haul flying in unpressurised planes and mountain climbing. It is important you say you have sickle cell trait before undertaking such activities as you may need to breathe oxygen. Extreme exercise may also precipitate problems and if you are a professional athlete you should have a training programme that takes account of this.

The trait is not an illness, but if you are planning to have children, then certain factors have to be considered.

If your partner does not have sickle cell trait, then any children you have will not have sickle cell disorder, but they could have the trait (50% chance).

If you and your partner both have the trait, there is a 25% chance that any child conceived may have sickle cell disorder and 50% chance they will have the trait.