

NHS Newborn Blood Spot Screening Programme

SCID screening: helping you decide if you want this for your baby

The NHS is considering introducing screening for severe combined immunodeficiency (SCID). SCID makes it very hard to fight off common infections like pneumonia and meningitis. Screening would help to find and treat babies with this condition earlier.



After about 3 months of age infections can be life-threatening for babies with SCID. Without treatment they rarely survive past the age of one.

You may have heard of babies with SCID having to live in a 'bubble' to avoid infections.

SCID affects about 16 babies a year in England. This works out at about 1 in every 40,000 births.

Screening your baby

The NHS offers newborn blood spot screening (using a heel prick to take blood) a few days after a baby is born. It looks for 9 rare but serious conditions, including sickle cell disease and cystic fibrosis.

Most babies will not have any of these conditions. For those who do, finding them early through screening is very important.

Early treatment can stop the baby becoming severely disabled or even save their life.

If the test, using a small fragment of DNA, shows your baby has fewer white blood cells than usual, it could be a sign they have SCID. White blood cells are important because they protect against infections.

No extra test needed

The test uses the same blood taken from the heel prick. No further blood sample will be taken. You have been provided with the 'Screening Tests For You and Your Baby' information which can help you make an informed choice for your baby.

SCID screening

We're offering screening for SCID in some hospitals to see how it could best be introduced across England. Your hospital is taking part. That's why you've been asked about it for your baby. You may be asked to take part in research linked to screening. It's ok to say no if you like.

Your choice

It is your choice whether or not to have the test for SCID. If you decide not to have it, we can still screen your baby for the 9 other conditions covered by newborn blood spot screening.

SCID results

Lower chance

Most babies will have a lower chance result, which means it is very unlikely they have SCID. In this case, you should get a letter by the time your baby is 6 weeks old to say they do not need any further tests for SCID.

Higher chance

About 1 in 2,500 babies will be found to be at higher chance of having SCID. If this is the case, you will be contacted within a few days and invited to see a professional who will offer you a diagnostic test for your baby. This will involve a blood test.

For every 100 babies found to have a higher chance of SCID, around:

- 6 will have SCID
- 87 will not have SCID
- 7 will have another problem and will be offered further information and support

This is shown in the graphic below.

For every 100 babies found to have a higher chance of SCID:



BCG vaccine

If your baby is offered the BCG vaccine it is important that the BCG clinic has your baby's SCID screening result before the vaccine is given.

This is because the treatment for SCID is more complicated if a baby has had the BCG vaccine.

Treatment

Treatment for SCID is far more likely to be successful if started early, rather than waiting until a baby becomes ill.

If tests show your baby has SCID, a bone marrow transplant can fix their body's defences against infections. Some types of SCID respond to gene therapy. This involves replacing a defective gene in your baby's body with a healthy one.

Further information

You can visit the NHS website (search for 'SCID') which has further information to support people offered SCID screening. You can also talk to your midwife or GP. Screening Tests For You and Your Baby is available on the NHS website.