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

This information was created on behalf of the NHS. In this information, the word ‘we’ refers to the NHS service that provides screening.

The NHS is considering introducing screening for severe combined immunodeficiency (SCID). SCID makes it very hard to fight off 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. About 14 babies a year in England will have SCID.

Screening your baby

The NHS offers newborn blood spot screening (using a heel prick to take blood) when a baby is 5 days old. 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.

You have been provided with the Screening tests for you and your baby information (www.gov.uk/government/publications/screening-tests-for-you-and-your-baby) which can help you make an informed choice about screening tests for your baby.

Same sample

The test for SCID uses the same blood taken from the heel prick. No further blood sample will usually need to be taken. Premature babies may need a second test because their immune system is still developing.

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.

SCID screening evaluation

We’re offering screening for SCID in some hospitals to see how it could best be introduced across England. Your hospital is one and that’s why you’ve been offered the test.

It is your choice whether or not your baby has the test for SCID.

If you decide that you want your baby to have the test, we will use your information as part of the evaluation.

If you decide you do not want your baby to have the test, we can still screen your baby for the 9 other conditions covered by newborn blood spot screening.

SCID results

Lower chance result

Most babies will get a lower chance result, which means it is very unlikely they have SCID. Parents will get the result by the time their baby is 6 weeks old.

Higher chance result

A higher chance result means it is more likely, but not certain, that your baby will have the condition.

We estimate that around 1 in 1,500 babies will get a higher chance result for SCID.

You will be contacted within a few days and invited to see a specialist team if your baby gets a higher chance result.

You will be offered a diagnostic test for your baby (blood test).

This diagnostic test will confirm if your baby:

- does not have SCID or another condition, and can be discharged
- has SCID
- has another condition affecting the immune system

One of the aims of the SCID evaluation is to find out how many babies are in each of these 3 groups.

BCG vaccine

Some parents will be offered the BCG vaccine for their baby. The BCG clinic will check your baby’s SCID screening result before giving it.

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

The BCG vaccine will only be offered if it is safe for your baby to have it.

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 an unhealthy gene in your baby's body with a healthy one.

More information and support

The NHS website has information about SCID at www.nhs.uk/conditions/baby/newborn-screening/blood-spot-test.

For support, you can talk to your midwife or GP.

Research

You may be contacted by researchers and asked to take part in research linked to newborn blood spot screening. Please tell your midwife if you want to take part or not. It is completely up to you and will have no effect on your care.

Confidentiality

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. PHE also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

First published August 2021. Updated April 2022.