UK NSC recommendation on screening for severe combined immunodeficiency (SCID)

Following a review of the evidence against strict criteria, the UK NSC recommends that screening for SCID should be evaluated in the NHS.

SCID refers to some rare inherited conditions which affect the development of the baby’s white blood cells. These are an important part of the immune system. SCID makes it difficult for babies to fight infections. Around 15 to 25 babies are born with the condition every year in the UK.

After about 3 months of age infections that are not serious in most babies can be life-threatening in those with SCID. The treatment is a bone marrow transplant, which can repair the damaged immune system.

Newborn screening, as part of the newborn blood spot screening programme, would look for babies with low numbers of white blood cells as a sign that they may have SCID.

Early detection can improve the success of the transplants. This is because doctors can help the baby to avoid infections before the transplant if they know the baby has SCID.

Key findings supporting the UK NSC recommendation

The UK NSC found that screening for SCID is likely to be effective in increasing the number of babies who survive before and after transplant. But the evidence is uncertain in some areas. For example, it is not known:

- how many healthy babies might be told they are ill when they are not (false positives)
- what care and treatment to offer babies with other conditions that cause low numbers of white cells
- how many babies are born in families who already know they have SCID
- how the laboratory and treatment services will cope with new tests and more ill babies

These, and other, issues can only be evaluated by trying screening for SCID in a large number of babies. The UK NSC is organising an evaluation to help its decision whether screening should be part of the newborn blood spot screening programme.

The UK NSC regularly reviews its recommendations on screening for different conditions in the light of new research evidence becoming available.

To find out more about the UK NSC’s recommendation on screening for SCID, please visit:

legacy.screening.phe.org.uk/scid