Newborn Screening for Severe Combined Immune Deficiency (SCID) Frequently Asked Questions

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Q 1: Why are SCID newborn screening tests performed in Australia and New Zealand?

Severe combined immune deficiency (SCID) is a group of genetic immune system disorders, with low or absent T cells. T cells are a type of white blood cell that fights infection. This means that babies born with SCID have a high risk of infections.

Around 1 in 60,000 babies born in Australia and New Zealand will have SCID. Newborn screening for SCID allows these babies to be diagnosed and treated early, which improves long term outcomes.

Newborn screening for SCID also enables early life saving treatment with bone marrow transplantation. This can cure SCID if performed early before babies with SCID have life-threatening infections.

Q 2. How are SCID newborn screening tests performed?

All babies born in Australia and New Zealand will have some blood taken from their heel in the first few days of life. This is tested for a range of rare medical conditions that are serious but treatable, including SCID. Early diagnosis of these conditions allows doctors to start the correct treatments before symptoms occur.

Q 3. When are further tests needed?

If there is an abnormal or borderline result from the SCID newborn screening test, further tests will be needed to confirm if your baby has SCID, or delayed development of their immune system, or another medical condition. It is also possible for some babies to have a normal immune system, but an abnormal or borderline newborn screening test result.

The only way to find out what your baby's result means is to have further tests.

While waiting for results of further tests, your baby should not receive any live vaccines, such as rotavirus. It is also important for you and your baby to avoid contact with people who are unwell, including people with cold sores or skin infections.

If further tests show that your baby has enough T cells, and does not have SCID or other medical conditions, no more tests are needed, and your baby should receive their routine vaccines.

If you have any concerns, please discuss these with your doctor, midwife or other health professional.

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