Why does my baby need more testing for severe combined immune deficiency (SCID)?

You have just learned that your baby needs more testing to find out whether he or she has a low number of a type of immune cell called T cells. The information in this leaflet will help you understand why this testing is necessary.

Newborn screening

A short time after birth some blood was collected from your baby's heel to screen for some rare disorders, including SCID, an immune problem due to low T cells. The goal of newborn screening is to identify conditions that we can treat if we catch them early, to improve the health of your baby.

Your baby's newborn screening result

The result on your baby was either not normal or did not give a clear result for the SCID screening test. The result could be caused by SCID, a less serious immune problem or prematurity. It is also possible to have an abnormal newborn screen for SCID, but have a normal immune system. Although the abnormal screening test may not necessarily mean your baby has SCID, your baby does need more testing.

Why does my baby need more testing?

Newborn screening tests alone cannot confirm or rule out disorders. A further blood test is needed to confirm whether a baby has low numbers of T cells. Your LMC (midwife or specialist) will work with you to help arrange for your baby to have this blood test within a few days of the newborn screening result.

Babies can look healthy at birth and still have SCID or related disorders. If not recognised and treated, these diseases can cause severe health problems.

The blood test: your LMC will arrange with the laboratory to have a small sample of blood taken from your baby, most likely by heel prick. The laboratory will use this to find out if your baby has low T cells.

About SCID

Severe combined immune deficiency is a rare genetic disorder affecting a person's immune system. The immune system is responsible for fighting off infection. Babies with SCID are born with little or no immune system. This means that they cannot fight off infections. Without treatment, even common infections can be life-threatening for babies with SCID. If your baby has SCID, we can start a treatment plan to help prevent the health problems SCID can cause.

Other immune system problems detected by newborn screening

As well as SCID, the screening test might pick up other conditions involving low numbers of immune cells. These are often not as severe as SCID, but it may also be important to find out about and treat them.

Treatment for SCID

The most effective treatment for SCID is a bone marrow transplant, which can cure babies of the condition. A transplant is best done before a baby gets a severe infection.

Treatment for immune conditions other than SCID

Babies with other immune conditions may need to receive medication.

Is SCID common?

SCID is not common. We expect that one or two babies will be born with SCID each year in New Zealand.

How will I know the results of my baby's further testing?

The further test results will likely take two to four days to come back. The immunology specialists at Starship Children's Health will contact your LMC to discuss the results as soon as they are back, and your LMC will contact you as soon as possible.

What happens if my baby's further test is not normal?

If the result of the further testing suggests there is a problem with your baby's immune system, a paediatrician will need to see your baby. Some babies may need to be hospitalised. The paediatrician will be able to tell you more.

What should I do right now?

While you are waiting to receive the results of the further testing, there are a few things to be aware of. Talk to your doctor before your baby has any vaccinations. In particular, any baby suspected of having SCID should not receive the rotavirus vaccine until the baby's immune system has been further tested. Your baby should not be around anyone who may be sick.

Further information

If you have any questions or concerns, call your LMC or your doctor.

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