

# My baby has low T cells



**You have just learned that your baby's blood test shows that your baby has a low number of a type of immune cell called T cells. Your baby now needs to see a paediatrician. The information in this leaflet will help you understand why this is necessary.**

## Your baby's test result

Your baby's result for the severe combined immune deficiency (SCID) newborn screening test was not normal. A further blood test was taken to find out if there is a possible problem with your baby's immune system. The results of the follow-up blood test are back, and show your baby's immune system may not be working as we expect it to. It shows your baby has a low number of T cells.

## Next steps

The immunology specialists at Starship Children's Health in Auckland have contacted your LMC (midwife or specialist) to discuss the next steps. A paediatrician now needs to see your baby as soon as possible. Your LMC will talk to you about the T cell test result, and about arranging for a paediatrician to see your baby at the hospital.

## What problems cause low T cells?

Severe combined immune deficiency can cause low T cells. So can other conditions. The cause of your baby's low T cells may be an immune problem that is not as serious as SCID. If this is the case, it is still important that we find out about the problem and treat it.



Sometimes babies can have low T cells (due to other medical problems) but still have a normal immune system.

Babies can look healthy at birth and still have SCID or related disorders. If we do not recognise and treat these disorders, they can cause severe health problems.

## 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.

## 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. Your immunologist will be able to tell you more.

## Is SCID common?

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

## Your specialist appointment

The paediatrician who sees your baby will:

- talk to you about your baby and family
- examine your baby
- arrange some additional blood tests.

These additional blood tests will help the immunologists to decide if your baby has SCID or another cause of low T cells.

There is a chance your baby may need to be started on medications. There is also a chance your baby may need to be admitted to hospital. Your paediatrician or immunologist will be able to tell you more.

## What should I do right now?

- Your baby should not be around anyone who may be sick. This includes members of your immediate family.
- Your baby should avoid crowded areas and daycare.
- Anyone looking after your baby or holding your baby should carefully wash their hands with soap and water first.
- If you are making up formula feeds for your baby, make sure you use cooled boiled water (boiled for at least 3 minutes and letting it cool).
- If your baby needs blood products, you will need to discuss this with the immunologists at Starship Children's Health as special precautions would be needed.
- Call your baby's doctor if your baby is unwell.
- Your baby should not have any vaccinations until seen by a paediatrician or you have a normal T cell result. In particular, any baby suspected of having SCID should not receive the rotavirus vaccine until the baby's immune system has been further tested.

## Further information

If you have any questions or concerns before you see the paediatrician, call your LMC or your baby's doctor.