Sláinte Leanaí Éireann
Children's Health Ireland

mychild.ie

National Newborn Bloodspot Screening Programme

Information for parents of babies at risk of SCID

How was my baby found to be at risk of SCID?

Your baby's heel prick screening test showed that they are at risk of having severe combined immunodeficiency (SCID).

This leaflet explains what SCID is, what happens next, and where to get support.

At this stage, we don't know whether your baby has SCID.

For this reason, your baby needs to come to hospital to:

- be seen by a doctor, and
- have an urgent specialist blood test.

This is to find out if they have SCID or not.

What is SCID?

Severe combined immunodeficiency (SCID) is an inherited condition.

SCID is a rare condition but is very serious.

Babies born with SCID have a very weak immune system. Their body does not make enough T-cells. T-cells are a type of immune cell that fights infection.

Early detection and treatment are very important. Common infections can be life-threatening for babies with SCID if they do not get treatment.

How likely is it that my baby has SCID?

Most babies who screen positive for SCID will not have the condition, but for those who do, early treatment is very important.

It is very important for your baby to have an urgent blood test so we can be sure if they have SCID or not.

What causes SCID?

SCID is an inherited condition. It is caused by a gene passed down from parents to their child.

Can SCID be treated?

Yes. SCID can be treated successfully. The earlier treatment starts, the better for your baby.

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What happens next?

Your baby needs to come to hospital to be seen by a doctor.

They will have an urgent specialist blood test to find out if they have SCID or not. The blood sample will be taken in hospital.

The blood sample will be sent to the laboratory and tested to check your baby's immune system.

When will I get the result of the blood test?

The result of the blood tests should be available the same day or the next day.

You may be asked to stay in hospital until the result is available.

If your baby is well, you may be able to go home to wait for the test result.

What happens when I get the result of my baby's blood test?

The result of your baby's blood tests may show that:

1. Your baby **does not have SCID** and their immune system is normal and healthy.

   If the test result is normal, your baby does not need further medical care. You will receive a parent information leaflet with more information about the normal blood test result.

   or

2. Your baby **has SCID** and needs expert medical care straight away.

   If your baby has SCID they will be transferred to Children's Health Ireland (CHI) at Crumlin, Dublin.

   They will receive expert care from the doctors in CHI at Crumlin.

   You will receive a parent information leaflet with more information about the blood test result and next steps.

   or

3. Your baby **does not have SCID, but might have another less serious condition affecting their immune system.**

   If this happens, the doctors from CHI Crumlin will contact you to arrange an appointment for your baby.

   Your baby will have further tests to find out whether they have a condition affecting their immune system.

   These kinds of conditions can be managed effectively by the specialist doctors in CHI at Crumlin.

   You will receive a parent information leaflet with more information about the blood test result and next steps.

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What do I need to do now?

Please bring your baby to the hospital at the date, time and location you have been given. Your baby will be seen by a doctor and will have blood tests taken.

Babies with SCID have a very weak immune system and can get very sick from common infections. Until we know whether your baby has SCID, we need to be very careful to keep the risk of infection as low as possible.

When you get to hospital, your baby will be seen by a doctor in a single room in the hospital, away from other patients. Please do not be alarmed by this.

The doctors who care for your baby will be wearing masks and gowns. Their protective equipment is an important measure to help keep the risk of infection as low as possible for your baby. This is in case they do turn out to have SCID or another condition affecting their immune system

When you are walking through the hospital, if possible, please put a **loose** cover over the car seat or pram that your baby is in, if you have one. This cover must be a light cotton cloth or muslin, or a rain cover for your car seat or pram.

It is very important that the cover is loose so that air can circulate for your baby. It is very important to keep regularly checking that your baby is comfortable and breathing normally. Remove the cover as soon as possible.

If you are driving to hospital in your own car **do not** put a cover over the baby's car seat until you get to the hospital.

I still have questions, who can I ask?

For more information, talk to the medical team caring for your baby in your local maternity hospital or unit.