Sláinte Leanaí Éireann
Children's Health Ireland

mychild.ie

National Newborn Bloodspot Screening Programme

Information for parents of babies at risk of SCID -

What to do while waiting for your baby's specialist blood test result

Why did my baby need a specialist blood test?

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

SCID is a very serious conditions that affects the immune system.

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

Your baby has been seen by a doctor and had an urgent specialist blood test to help us find out whether they have SCID or not.

Your baby's blood sample has been sent to the laboratory and is being tested to check your baby's immune system.

When will I get the result of the specialist blood test?

The result of the blood test should be available within 24 hours.

What do I need to do while I wait for the blood test result?

Babies with SCID have a very weak immune system. They 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.

If your baby is staying in hospital

If your baby is staying in hospital until the blood test result is available, doctors will take care to keep the risk of infection as low as possible.

Your baby will be cared for in a single room.

Doctors and nurses will take extra precautions when caring for your baby such as wearing gowns, masks and gloves. Please do not be alarmed by this.

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.

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If you are bringing your baby home

If you are bringing your baby home to wait for the blood test results, please follow this advice:

Keep your baby at home:

If possible, your baby should be kept at home until the result of the specialist blood test is available.

If anyone in your home is unwell:

Please tell the doctor or nurse in the maternity hospital or unit if anyone in your home is unwell and has symptoms of infection, for example a cough, runny nose, fever, sore throat, diarrhoea, vomiting, rash, cold sores.

Try and make sure your baby is cared for by an adult away from the person or people who might be unwell, and if possible in a different room.

Older siblings (brothers or sisters):

If your baby has older brothers or sisters, they can continue to interact with your baby if they are well and don't have any symptoms of infection, for example a cough, runny nose, fever, sore throat, diarrhoea, vomiting, rash, cold sores.

They should wash their hands when they get home from school or childcare.

Visitors:

If possible, do not allow any visitors to come to your home.

Keep your baby away from anyone with symptoms of infection, for example a cough, runny nose, fever, sore throat, diarrhoea, vomiting, rash, cold sores.

If you need to have visitors, they should be healthy adults only. Your baby should not have any contact with children, except their siblings. Visitors should wash their hands very carefully when they arrive at your home. They should not kiss your baby at all. They should not touch your baby's face or hands.

How should I feed my baby?

If you are breastfeeding or expressing breast milk, please continue to do so unless you are advised differently by the doctors.

If you are bottle feeding, make sure to wash and sterilise bottles, teats, expressing and feeding equipment carefully.

If you are using formula milk, use liquid (pre-made) formula whilst waiting for the test result if possible. It is sterile and convenient.

If using powdered formula milk, take extra care when preparing your bottle for your baby. See mychild.ie for information on how to prepare powdered formula milk.

Throw away any made-up formula left in the bottle within 2 hours.
Use a fresh feed after 2 hours if your baby is a slow feeder.

Version: 1
Issue Date: April 2026

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What should I do if my baby becomes unwell at home while waiting for the test results?

We do not expect your baby to become unwell while waiting for the blood test result.

Contact your local hospital if your baby develops any of these symptoms:

- fever (temperature of 38 degrees Celsius or above)
- persistent poor feeding
- persistent vomiting or diarrhoea
- fast or difficult breathing
- unusual sleepiness. Newborn babies can sleep for long periods of time. But seek medical advice urgently if your baby is sleeping for extremely long periods and is difficult to wake.
- any new rash
- any signs that worry you

If you need to contact the hospital or bring your baby to hospital, tell the healthcare professionals that:

- your baby has had a positive newborn screening result for SCID and might have a weakened immune system, and
- you are waiting for the result of a specialist blood test to find out whether your baby has SCID.

How will I get the results of the specialist blood test?

When the results of the specialist blood test are available, the Paediatric Immunology team in Children's Health Ireland (CHI) at Crumlin will contact you directly to discuss the results.

The hospital where your baby had the blood test taken will also contact you directly.

Please make sure your phone is charged and switched on while waiting for blood test results.

What will happen then?

The result of your baby's blood test 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.

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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 Children's Health Ireland (CHI) at Crumlin, Dublin, 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.

I have more questions – who can I ask?

Waiting for blood test results can be an anxious time. It is completely natural to feel worried.

If you have questions, you can speak with:

- Your local paediatric or neonatology team caring for your baby
- Your public health nurse or post-natal hub or GP for general support.

Version: 1
Issue Date: April 2026