Sláinte Leanaí Éireann
Children's Health Ireland

mychild.ie

National Newborn Bloodspot Screening Programme

Information for parents – SCID is likely

Your baby's heel prick test showed that they were at risk of having a condition called severe combined immunodeficiency (SCID).

Because of this, your baby had a specialist blood test to find out whether they have SCID.

What did the blood test show?

The results of the blood test show that it is **likely that your baby does have SCID.**

We understand that this is very worrying for you. Please be reassured that your baby will receive the best possible care from the expert Paediatric Immunology team in Children's Health Ireland (CHI) at Crumlin.

There are very good treatments available.

The Paediatric Immunologist will discuss the treatment options with you and expected outcomes for your baby.

Treatment should start as soon as possible. We know that babies with SCID do much better if treated early.

The Paediatric Immunology team in CHI at Crumlin will arrange to see you very soon.

We do not expect your baby to become unwell over the next few days (See page 5 for information on symptoms to look out for).

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.

What happens next?

The Paediatric Immunology team in CHI at Crumlin will arrange for your baby to be admitted to hospital for specialist care very soon.

You will be contacted by the hospital as soon as a bed is available for your baby.

Please make sure your phone is charged and switched on while waiting to hear from CHI at Crumlin.

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In the meantime, it is very important that your baby is protected from any risk of infection.

If you are caring for your baby at home, please follow this advice:

1. Limit contact with other people

Keep your baby at home:

Unless advised otherwise, your baby should be kept at home until they go to CHI at Crumlin.

If you need to leave the home, please try to avoid crowded places as much as possible, for example, shops, cafés, public transport and family gatherings.

Please tell the doctor or nurse at 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, if possible in a different room.

It is important that parents to continue to bond with your baby. Parents can kiss the baby as long as they avoid the baby's face and hands.

Other siblings (brothers and 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.

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

Avoid having 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. Do not bring your baby into contact with children, other than their siblings.

Visitors should wash their hands very carefully when they arrive at your home.

Visitors should not kiss your baby at all. They should not touch your baby's face or hands.

2. Hand hygiene is essential

When caring for your baby, you should wash your hands thoroughly with soap and water:

- before doing skin to skin or touching your baby
- before feeding or handling bottles
- after using the toilet.

Alcohol hand gel can be used when handwashing isn't possible.

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3. Feeding your baby

If you are breastfeeding:

Cytomegalovirus (CMV) is a viral infection that can sometimes be passed on from a mother to her baby in breast milk.

Babies with a weak immune system can become sick if they get an infection with CMV.

If you are breastfeeding your baby, we will take a blood test from you. This is to check whether you have the CMV virus.

You will be asked to stop breastfeeding until we have the results of the CMV test.

You will be asked to feed your baby formula milk feeds only until we have the results of the CMV test.

You can hand express and use a rental grade breast pump to express your breast milk while waiting for the test. Talk to your midwife or public health nurse about getting a suitable breast pump.

Store expressed breast milk in the fridge for up to 7 days or in the freezer for longer periods.

If you don't have the CMV infection, you will be able to breastfeed directly at the breast again.

If you have the CMV virus, you will need to stop giving your baby breast milk feeds. If this happens, staff will support you to stop breastfeeding safely. It is best to stop expressing gradually and not suddenly. This helps to reduce the risk of breast discomfort and infection.

How to formula feed:

For formula 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 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.

If you have any concerns about feeding your baby, discuss them with the doctors who are caring for your baby.

4. Vaccinations

Your baby should not receive any vaccinations until advised otherwise by your doctor.

If your baby has had the RSV vaccine, do not worry. This is safe and helps protect your baby from RSV.

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Family members who are in close contact with the baby should not receive the nasal flu vaccine. This is usually offered to children aged 2 to 17 during flu season.

Other routine vaccinations for household members are encouraged. Before getting a vaccine, tell your GP (family doctor) there is a baby with likely SCID in the home.

Please talk to your GP or the Paediatric Immunology team if you have any concerns about vaccinations for you or your family members.

5. Pets

There is no need to remove household pets.

You should:

- wash your hands after handling pets
- keep pets away from areas where you and your baby feed and sleep
- make sure pets do not have any direct contact with your baby.

What should I do if my baby becomes unwell while waiting for a bed at CHI at Crumlin?

We do not expect your baby to become unwell while you are waiting for admission to CHI at Crumlin.

The Paediatric Immunology team in CHI at Crumlin are arranging an urgent admission for your baby.

You will be contacted by the hospital as soon as a bed is available for your baby.

Please make sure your phone is charged and switched on while waiting to hear from CHI at Crumlin.

Please seek urgent medical care 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 seek urgent care for your baby, tell the healthcare professionals that:

- your baby has had a positive newborn screening result for SCID and might have a weakened immune system, and
- your baby is waiting to be admitted to CHI at Crumlin for care under the Paediatric Immunology team.

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What should I do when I arrive at CHI at Crumlin?

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.

When you get to the hospital, go directly to the admissions department and tell them you have arrived. You will be told which ward and room to go to. A member of the CHI nursing and medical team will meet you and your baby shortly after arrival.

I still have questions, who can I ask?

Waiting to bring your baby to hospital can be very worrying.

If you have questions, use the contact number you have been given for the Paediatric Immunology team, or phone:

- Monday to Friday (9am to 5pm): Phone 01-4096893 (secretary)
- Out of hours: 01-4096100 (ask for the Consultant Paediatric Immunologist who is on-call)