Sláinte Leanaí Éireann
Children's Health Ireland

mychild.ie

National Newborn Bloodspot Screening Programme

Information for parents of babies with T-cell lymphopenia

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 **they dao not have SCID**. This is good news.

However, your baby **does have** a low number of T-cells. This is called **T-cell lymphopenia.**

What is T-cell lymphopenia?

T-cell lymphopenia is where your baby has a lower number of T-cells than expected.

T-cells are a type of white blood cell that help the body fight infections.

Babies with a low number of T-cells may have a weak immune system. This means that common infections could be very serious.

What causes T-cell lymphopenia?

T-cell lymphopenia has many different causes. Some are not serious and will get better over time. Others are more serious and will need treatment.

We need to do further tests. These are to find out what has caused the T-cell lymphopenia and what this means for your baby.

Can T-cell lymphopenia be treated?

T-cell lymphopenia has many different causes.

Many patients with T-cell lymphopenia do not become unwell. Their immune system often becomes stronger as they grow.

Patients with T-cell lymphopenia may need to be monitored by a doctor, but they often do not need intensive treatment.

When we find out what is causing T-cell lymphopenia in your baby, your doctor can advise on the best treatment.

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What happens next?

The Paediatric Immunology team in Children's Health Ireland (CHI) at Crumlin will phone you to discuss your blood test result and to arrange an appointment and further tests for your baby in CHI at Crumlin.

The appointment will be within 1 week of the phone call.

These tests will help the doctors to find out:

- why your baby has a low number of T-cells, and
- whether any treatment is needed.

How to care for your baby in the meantime

T-cells help fight infections. This means babies with T-cell lymphopenia can be more at risk from infections.

Please take care to keep the risk of infection low until your baby is seen by doctors in CHI at Crumlin.

When the doctors have seen your baby and done more tests, they can give you more advice on how to keep the risk of infection low.

For now, please follow this advice:

1. Hand hygiene

Hand hygiene is very important.

Wash your hands thoroughly with soap and water:

- before doing skin to skin or touching your baby
- before feeding your baby or giving them medication
- after changing nappies
- after coming home from outside.

Ask visitors to clean their hands before holding your baby.

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

2. Limiting exposure to illness

Try to avoid close contact with anyone who is unwell with a fever, cough, cold, vomiting, diarrhoea, rash, cold sores. This includes adults and children.

Limit visitors to your home to adults and children who are well. It's okay to say: "Our baby's immune system is still developing — please visit another time."

It is best to avoid crowded indoor spaces with your baby for now, for example, busy shops and large gatherings.

Avoid close contact with people recently exposed to infections.

Outdoor walks are encouraged and safe.

Version: 1
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3. Siblings (brothers and sisters)

Siblings can continue with their normal activities such as school or creche.

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

If a sibling has symptoms of infection, they should avoid contact with the baby as much as possible.

4. Vaccinations

Babies don't get their routine vaccinations until they are 2 months old.

Make sure your baby does not get any vaccinations before they are seen by the Paediatric Immunology team in CHI at Crumlin.

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

The Paediatric Immunology team will give you clear and individual guidance on vaccinations for your baby.

All other family members should stay up to date with their own vaccinations, including:

- flu vaccine
- COVID-19 vaccine
- routine school vaccines.

This helps protect your baby.

5. Feeding your baby

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

If you use formula, make sure bottles, teats and feeding equipment are sterilised carefully. Prepare the formula exactly as instructed.

More information on feeding your baby is available on mychild.ie

6. Medication

In some cases, the Paediatric Immunology team may advise starting your baby on antibiotic medication to help prevent infection.

If this is necessary, the team will discuss medication (including benefits and possible side effects) with you.

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When to seek medical advice urgently

We do not expect your baby to become unwell while they are waiting to be seen by the doctors in CHI at Crumlin.

Seek medical advice urgently if your baby has:

- 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 medical care before you see the Paediatric Immunology team, tell the doctor that your baby:

- has T-cell lymphopenia, and
- is waiting to be seen by the Paediatric Immunology team in CHI at Crumlin.

I still have questions, who can I ask?

Waiting to bring your baby to hospital can be a worrying time.

If you have questions, please contact the Paediatric Immunology team.

Phone 01-4096893 (secretary) from Monday to Friday (9am to 5pm).

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