National Newborn Bloodspot Screening Programme

Follow up of a baby who screened positive for severe combined immunodeficiency (SCID)

Guidance for paediatricians and maternity hospital/units

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Dear Colleagues,

The National Newborn Bloodspot Screening Programme (NNBSP) has prepared this pack to support maternity hospital/ units in providing follow up for babies who screen positive for severe combined immunodeficiency (SCID) through newborn bloodspot screening.

A positive screening result is not diagnostic. A positive screening result indicates only that a baby is at increased risk of SCID (or another condition affecting their immune system). Babies who screen positive for SCID need urgent clinical review and confirmatory testing (flow cytometry) to determine whether they have SCID. **The maternity hospital/ unit of birth is asked to arrange this follow up.**

This pack contains all the information and resources you will need to arrange and provide clinical review and confirmatory testing for babies who screen positive for SCID. The pack contains 11 documents. Please read Document 1 first – it contains a summary of the follow up required and information on when to use/ refer to the other documents contained in the pack.

Documents contained in this pack:

1. Summary of guidance for maternity hospitals/ units (DLPs/ Midwifery/ Neonatologists/ Paediatricians) – Follow up of a baby who has screened positive for SCID
2. Clinical evaluation form – baby who has screened positive for SCID
3. Guidance for maternity hospitals/ units – Infection prevention and Control (IPC) measures for babies who have screened positive for SCID
4. Detailed information to support maternity hospitals/ units communicating SCID screen positive result to parents
5. Information for parents of babies at risk of SCID
6. Information for parents of babies at risk of SCID – what to do while waiting for your baby's specialist blood test result
7. Infection Prevention and Control (IPC) measures for maternity hospitals/ units – baby with suspected or confirmed SCID
8. Information for parents – SCID is likely
9. Information for parents of babies with T-cell lymphopenia
10. Babies with normal test results for SCID – information for parents
11. Severe combined immunodeficiency (SCID) – Technical information for healthcare professionals
12. SCID/ADA-SCID Laboratory Request Form

The NNBSP would like to thank you for your continued support in providing follow up for screen detected babies at increased risk of rare conditions. If you have any questions or feedback, please do not hesitate to contact the programme at child.screening@hse.ie

Yours Sincerely,

Dr Abigail Collins MBBS, MPhil, MFPHMI, FFPH (UK)
Consultant in Public Health/Medical Officer of Health (MCRN 404629)
National Clinical Lead Child Health Public Health / National Healthy Childhood Programme

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Summary of guidance for maternity hospitals/ units (DLPs/ Midwifery/ Neonatologists/ Paediatricians) – Follow up of a baby who has screened positive for SCID

Why am I receiving this leaflet?

You are receiving this leaflet because a baby born under the care of your maternity services has screened positive for severe combined immunodeficiency (SCID) through newborn bloodspot screening.

The screening result is not diagnostic. A positive screening result indicates only that a baby is at increased risk of SCID (or another condition affecting their immune system). This baby now needs urgent clinical review and confirmatory testing (flow cytometry) to determine whether they have SCID. You are asked to arrange this follow up.

SCID screening can result in detection of

1. **SCID** – the most serious form of primary immunodeficiency, with a combined absence of T-cell and B-cell function. The incidence of SCID in Ireland is estimated at approximately 1 in 40,000 births.
2. **Non-SCID T-cell lymphopenia (TCL)** – a clinically heterogeneous group with a diverse range of underlying causes. While not the target of screening, early detection of non-SCID TCL may result in improved clinical outcomes for some babies.
3. **False positives** – As with all screening programmes, SCID screening may result in false positive cases, where the screening result is positive but, on confirmatory testing, the baby is found to have neither SCID nor a non-SCID TCL.

(For more information on SCID and Non-SCID TCLs, please see **Document 11- Technical information for healthcare professionals**).

It is estimated that approximately 20 babies may screen positive for SCID each year in Ireland, of whom approximately 1 may be found to have SCID on confirmatory testing, 7 may be found to have a non-SCID TCL and 12 may be found to be false positives.

What is my role?

You are asked to:

- locate the baby and communicate the screening result and next steps to the parents
- arrange prompt clinical review of the baby, confirmatory testing (flow cytometry), and paediatric immunology input.

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This leaflet explains what to do. The guidance provided in this document is summarised in Figure 1 – flow chart (pages 10-11).

The Paediatric Immunology Team, Children's Health Ireland (CHI) at Crumlin, will support you in providing follow up and onward care for babies who screen positive for SCID – see further information below. If clinical review and/ or confirmatory testing indicates that a diagnosis of SCID is likely/ confirmed the Paediatric Immunology Team will take over the care of the baby in CHI at Crumlin. The Paediatric Immunology team will also arrange to follow up all babies with suspected non-SCID TCL on confirmatory testing.

What is SCID?

SCID is the most serious form of primary immunodeficiency, with a combined absence of T-cell and B-cell function.

SCID is an inherited disorder. There are at least 20 different genetic variants that can cause SCID.

Without treatment, patients with SCID generally do not survive longer than one year, typically dying as a result of severe infection (including from live vaccination), malignancy, and/ or complications from immune dysregulation.

Babies with SCID are typically asymptomatic at birth, and most do not have a positive family history of the condition.

Treatment of SCID aims to restore a functional immune system through haematopoietic stem cell transplantation (HSCT) or gene therapy. Early detection and treatment are associated with better clinical outcomes.

Babies with SCID are cared for by the Paediatric Immunology Team, CHI at Crumlin.

Follow up care for babies with non-SCID TCL will also be managed by the Paediatric Immunology team. Treatment of non-SCID TCL will depend on the underlying cause.

What immediate clinical action do I need to take?

The immediate clinical action required depends on whether the baby is

1. at home with their parent(s)/ legal guardian(s) (hereafter referred to as 'parents') (pages 3-5)
2. already admitted under your care (i.e. baby is clinically unwell) (pages 6-7)
3. mother is admitted under your care, and baby is in hospital with mother but is clinically well (pages 8-9).

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1. Baby is at home with their parents

If the baby is at home with their parents:

a) Arrange clinical review of the baby, ideally same day.

Arrange an urgent clinical review for the baby by the paediatric team, **ideally same day.**

At this clinical review, the paediatrician is asked to undertake a clinical evaluation of the baby **(Document 2 - Clinical evaluation form - baby who has screened positive for SCID)** and to take blood samples for confirmatory testing (flow cytometry) and FBC.

The baby should be reviewed with their parents in a single room and protective isolation precautions should be instituted to protect the baby from infection. Details of the relevant infection control measures are provided in **Document 3 – IPC measures for babies who have screened positive for SCID**.

b) Inform the parents

Phone the parents to tell them about the screening result and provide details of the clinical evaluation (time, date, location etc.).

When communicating with the baby's parents, it is important to:

- emphasise that the screening result is not diagnostic. It indicates only that the baby is at increased risk of SCID. Further testing is now required, that will help us find out whether the baby has SCID.
- if further tests indicate that the baby might have SCID, reassure the parents that effective treatments are available. Early detection allows timely treatment and usually, good outcomes.
- ask the parent for an email address and advise them that you will send further parent information immediately after the phone call **(Document 5 – Information for parents of babies at risk of SCID)** to support them in understanding the screening result and next steps.

See **Document 4 – Detailed information to support maternity hospitals/ units communicating SCID screen positive result to parents** for more information and advice on how to communicate a positive newborn screening result for SCID and next steps to parents over the phone.

c) Follow up electronic communication with parents

After the phone call, immediately send parents a follow up electronic communication with:

- details of the clinical evaluation (location, time, date etc.)
- **Document 5 – Information for parents of babies at risk of SCID**
- Send this information to the email address they have provided.

d) Paediatric team to undertake clinical review of the baby and take blood samples

How to undertake the clinical review:

- As described above, the baby should be reviewed with their parents in a single room and protective isolation precautions should be instituted to protect the baby from infection. Details

of the relevant infection control measures are provided in **Document 3 – IPC measures for babies who have screened positive for SCID**.

- A history and physical examination should be undertaken, guided by **Document 2 – Clinical evaluation form - baby who has screened positive for SCID**. Details of the history and physical examination should be recorded on this form, and the form should be emailed to the Paediatric Immunology team, after the clinical review at immunology@childrenshealthireland.ie
- The following **laboratory investigations** should be undertaken **urgently**

  1) **1ml EDTA for flow cytometry** – Use the laboratory request form provided to you by the Clinical Liaison Nurse from the NNBSL (see Appendix). Request 'SCID Screen for Immunology' and send the fresh EDTA sample, through your local laboratory, at room temperature, without delay, e.g. by taxi, directly to the Immunology Lab, Saint James's Hospital, Dublin (sample to arrive Monday-Thursday, or no later than 12 noon on Friday)
  2) **FBC –** for urgent analysis in local laboratory

e) Immediate liaison with Paediatric Immunology Team

Immediately following the clinical evaluation:

- ask the parents to wait while you discuss your findings and next steps with the Paediatric Immunology team
- email the clinical evaluation form (**Document 2 - Clinical evaluation form - baby who has screened positive for SCID**) to the Paediatric Immunology Team at immunology@childrenshealthireland.ie
- phone the Paediatric Immunology consultant on call to discuss the case and management required.

> **Contact details for Paediatric Immunology, CHI at Crumlin:**
>
> **Phone: 01 4096100 (CHI Crumlin Switchboard) & Bleep 8524/8426/8647/ Immunology registrar on call**

Further management of the baby will depend on whether they are well enough to go home or require hospital admission.

- **If the baby is considered well enough to go home**, give the parents **Document 6 – Information for parents of babies at risk of SCID – What to do while waiting for your baby's specialist blood test result.** This document includes information on the IPC precautions parents need to keep their baby safe at home while confirmatory test results are awaited.
- **If the baby demonstrates clinical features that merit hospital admission**, admission should be arranged in your hospital/ unit following the infection control precautions outlined in the **Document 7 – IPC measures for maternity hospitals/ units – Baby with suspected or confirmed SCID** pending the results of the confirmatory testing.

If a suitable cot/ cubicle is not available in your unit at the time, and hospital admission is deemed necessary, liaise with the Paediatric Immunology team in CHI to explore alternative arrangements.

A treatment plan should be made in conjunction with the Paediatric Immunology team.

Give the parents **Document 6 – Information for parents of babies at risk of SCID – What to do while waiting for your baby's specialist blood test result.** This provides more information for parents on next steps.

f) Action once confirmatory test results (flow cytometry) are available

The results of confirmatory testing will be available within 24 hours of the sample arriving at SJH Immunology lab. The Paediatric Immunology team will communicate the results and their clinical significance directly to you and your team and directly to the baby's parents. In line with good practice, as the baby is under the care of your service you are also asked to communicate the confirmatory test results to the parents.

If the confirmatory test results suggest SCID or another significant immunodeficiency:

- Arrangements will be made for urgent transfer of the baby to CHI at Crumlin for further investigation and treatment. The Paediatric Immunology team will liaise with you and with the baby's parents to arrange this.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will be taking over care of the baby in CHI at Crumlin.
- You are asked to provide the parents with **Document 8 – Information for parents - SCID is likely** which provides more information on the confirmatory test result and next steps.

If the confirmatory test results suggest non-SCID TCL:

- An appointment will be arranged with the Paediatric Immunology team in CHI at Crumlin. The Paediatric Immunology team will liaise directly with the baby's parents to arrange this.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will arrange to review their baby in CHI at Crumlin.
- You are asked to provide the parents with **Document 9 – Information for parents of babies with T-cell lymphopenia** which provides more information on the confirmatory test result and next steps.

If the confirmatory test results are normal (i.e. screening result was a false positive):

- The baby does not require any further investigations.
- The Paediatric Immunology team will contact the parents directly to discuss the test result and provide reassurance.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will contact them directly to discuss the test result.
- You are asked to provide the parents with **Document 10 – Babies with normal test results for SCID – information for parents** which provides more information on the confirmatory test result and provides reassurance.

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2. Baby is already admitted under your care (i.e. baby is clinically unwell)

If the baby is already an in-patient under your care or under the care of another Paediatrician/ Neonatologist in your unit because they are clinically unwell or premature:

a) **Inform the parents of the screening result** in person. **Document 4 – Detailed information to support maternity hospital/ units communicating SCID screen positive results to parents** may be helpful to support communication of screening result to parents.

b) **Give parents the relevant parent information leaflet** - **Document 5 – Information for parents of babies at risk of SCID.**

c) **Institute protective isolation precautions** as per **Document 7 – IPC measures for maternity hospitals/ units – Baby with suspected or confirmed SCID.**

d) **Paediatric team to undertake a clinical review of the baby** – history, physical examination and take blood samples as described in **Document 2 – Clinical evaluation form – baby who has screened positive for SCID.**

Details of the infant's history, physical examination and clinical progress should be recorded on the clinical evaluation form (**Document 2**) and the form should be emailed to the Paediatric Immunology team in CHI at Crumlin immediately after the clinical review at immunology@childrenshealthireland.ie

The following blood tests should be urgently requested

1) **1ml EDTA for flow cytometry** – Use the laboratory request form provided to you by the Clinical Liaison Nurse from the NNBSL (see Appendix). Request 'SCID Screen for Immunology' and send the fresh EDTA sample, through your local laboratory, at room temperature, without delay, e.g. by taxi, directly to the Immunology Lab, SJH, Dublin (sample to arrive Monday-Thursday, or no later than 12 noon on Friday).

2) **FBC** – for urgent analysis in local laboratory.

e) **Immediate liaison with Paediatric Immunology team**

Immediately following the clinical evaluation:

- email the clinical evaluation form (**Document 2**) to the Paediatric Immunology team at immunology@childrenshealthireland.ie
- phone the Paediatric Immunology consultant on call to discuss the case and management required.

Contact details for Paediatric Immunology, CHI at Crumlin:

Phone: 01 4096100 (CHI Crumlin Switchboard) & Bleep 8524/8426/8647/ Immunology registrar on call

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Following clinical review and discussion with the Paediatric Immunology team, if the baby is suspected to have either SCID or another clinically significant inborn error of immunity, arrangements will be made for urgent transfer of the baby to the Paediatric Immunology team, CHI at Crumlin, for further investigation and management.

Action once confirmatory test results (flow cytometry) are available

The results of confirmatory testing by flow cytometry will be available within 24 hours of the sample arriving at SJH Immunology lab. The Paediatric Immunology team will communicate the results and their clinical significance directly to you and your team and directly to the baby's parents. In line with good practice, as the baby is under the care of your service, you are also asked to communicate the confirmatory test results to the parents.

If the confirmatory test results suggest SCID or another significant immunodeficiency:

- Arrangements will be made for urgent transfer of the baby to CHI at Crumlin for further investigation and treatment. The Paediatric Immunology team will liaise with you and with the baby's parents to arrange this.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will be taking over care of the baby in CHI at Crumlin.
- You are asked to provide the parents with **Document 8 – Information for parents - SCID is likely** which provides more information on the confirmatory test result and next steps.

If the confirmatory test results suggest non-SCID TCL:

- An appointment will be arranged with the Paediatric Immunology team in CHI at Crumlin. The Paediatric Immunology team will liaise directly with the baby's parents to arrange this.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will arrange to review their baby in CHI at Crumlin.
- You are asked to provide the parents with **Document 9 – Information for parents of babies with T-cell lymphopenia** which provides more information on the confirmatory test result and next steps.

If the confirmatory test results are normal (i.e. screening result was a false positive):

- The parents can be reassured that the baby does not have SCID.
- The Paediatric Immunology team will contact the parents directly to discuss the test result and provide reassurance.
- You are also asked to inform parents of the SCID test result and advise them that the Paediatric Immunology team will contact them directly to discuss the SCID test result.
- You are asked to provide the parents with **Document 10 – Babies with normal test results for SCID – information for parents** which provides more information on the confirmatory test result and provides reassurance around the SCID screening result.
- Continue clinical care of the baby under your team and clinical governance as required.

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3. Mother is admitted under your care, and baby is in hospital with mother but is clinically well

a) **Inform the parents of the screening result** in person. (**Document 4 – Detailed information to support maternity hospital/ units communicating SCID screen positive results to parents** may be helpful to support communication of screening result to parents.)

b) **Give parents the relevant parent information leaflet** - **Document 5 – Information for parents of babies at risk of SCID.**

c) **Institute protective isolation precautions** as per **Document 3 – IPC measures for babies who have screened positive for SCID**.

d) **Paediatric team to undertake a clinical review of the baby** – history, physical examination and take blood samples as described in **Document 2 – Clinical evaluation form – baby who has screened positive for SCID.**

Details of the infant's history, physical examination and clinical progress should be recorded on the clinical evaluation form (**Document 2**) and the form should be emailed to the Paediatric Immunology team in CHI at Crumlin immediately after the clinical review at immunology@childrenshealthireland.ie

The following blood tests should be urgently requested

1) **1ml EDTA for flow cytometry** – Use the laboratory request form provided to you by the Clinical Liaison Nurse from the NNBSL (see Appendix). Request 'SCID Screen for Immunology' and send the fresh EDTA sample, through your local laboratory, at room temperature, without delay, e.g. by taxi, directly to the Immunology Lab, SJH, Dublin (sample to arrive Monday-Thursday, or no later than 12 noon on Friday).

2) **FBC** – for urgent analysis in local laboratory.

d) **Immediate liaison with Paediatric Immunology team**

Immediately following the clinical evaluation:

- Email the clinical evaluation form (**Document 2**) to the Paediatric Immunology team at immunology@childrenshealthireland.ie
- Phone the Paediatric Immunology consultant on call to discuss the case and management required.

Contact details for Paediatric Immunology, CHI at Crumlin:

Phone: 01 4096100 (CHI Crumlin Switchboard) & Bleep 8524/8426/8647/ Immunology registrar on call

Following clinical review and discussion with the Paediatric Immunology team, if the baby is suspected to have either SCID or another clinically significant inborn error of immunity, arrangements will be made for urgent transfer of the baby to the Paediatric Immunology Team, CHI at Crumlin, for further investigation and management.

Action once confirmatory test results (flow cytometry) are available

The results of confirmatory testing by flow cytometry will be available within 24 hours of the sample arriving at SJH Immunology lab. The Paediatric Immunology team will communicate the results and their clinical significance directly to you and your team and directly to the baby's parents. You are also asked to communicate the confirmatory test results to the parents.

If the confirmatory test results suggest SCID or another significant immunodeficiency:

- Arrangements will be made for urgent transfer of the baby to CHI at Crumlin for further investigation and treatment. The Paediatric Immunology team will liaise with you and with the baby's parents to arrange this.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will be taking over care of the baby in CHI at Crumlin.
- You are asked to provide the parents with **Document 8 – Information for parents - SCID is likely** which provides more information on the confirmatory test result and next steps.

If the confirmatory test results suggest non-SCID TCL:

- An appointment will be arranged with the Paediatric Immunology team in CHI at Crumlin. The Paediatric Immunology team will liaise directly with the baby's parents to arrange this.
- You are also asked to inform parents of the test result and advise them that the Paediatric Immunology team will arrange to review their baby in CHI at Crumlin.
- You are asked to provide the parents with **Document 9 – Information for parents of babies with T-cell lymphopenia** which provides more information on the confirmatory test result and next steps.

If the confirmatory test results are normal (i.e. SCID screening result was a false positive):

- The parents can be reassured that the baby does not have SCID.
- The Paediatric Immunology team will contact the parents directly to discuss the SCID test result and provide reassurance.
- You are also asked to inform parents of the SCID test result and advise them that the Paediatric Immunology team will contact them directly to discuss the test result.
- You are asked to provide the parents with **Document 10 – Babies with normal test results for SCID – information for parents** which provides more information on the confirmatory test result and provides reassurance.

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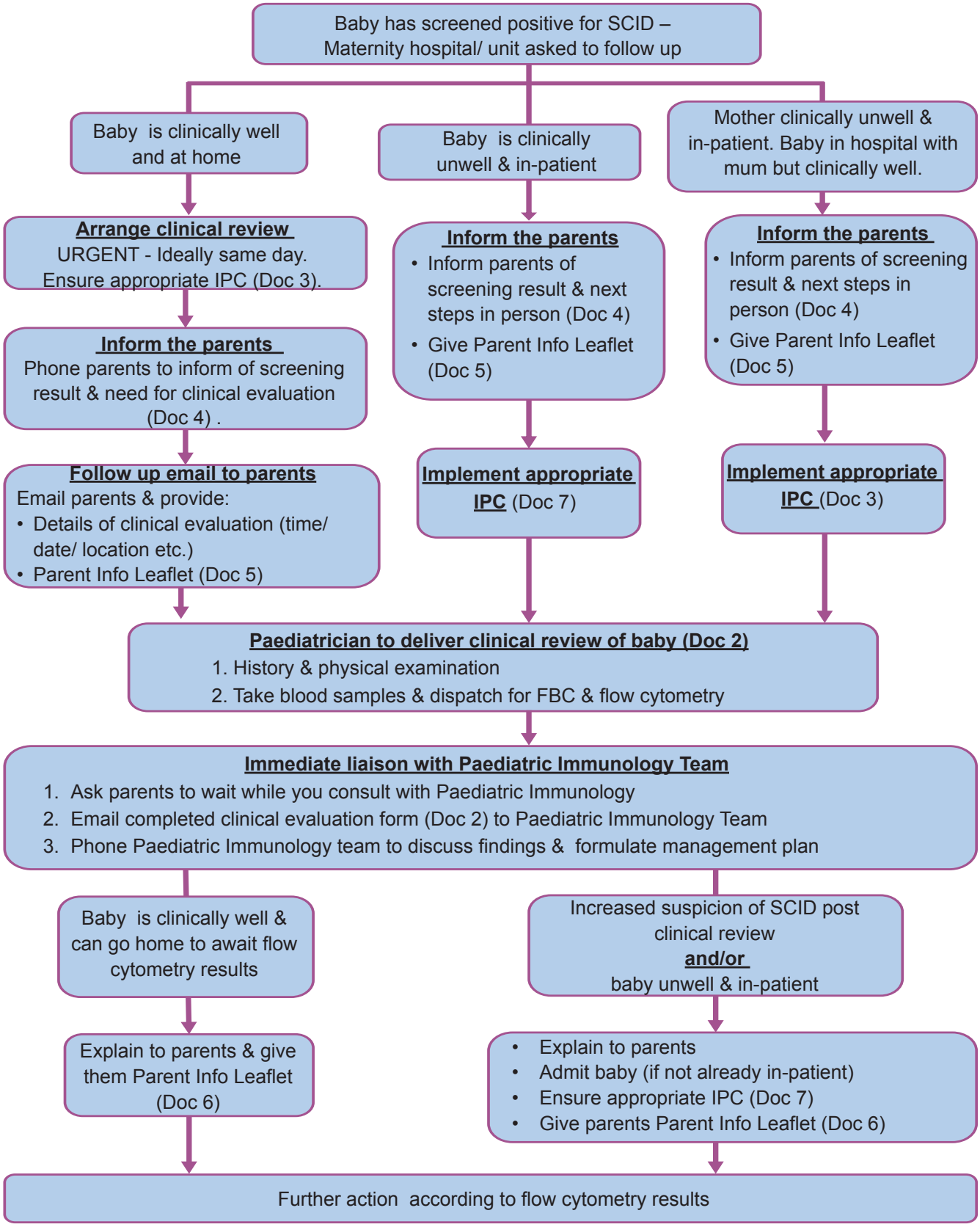
Figure 1: Guidance for maternity hospitals/ units (DLPs/ Midwifery/ Neonatologists/ Paediatricians) – follow up of a baby who has screened positive for SCID



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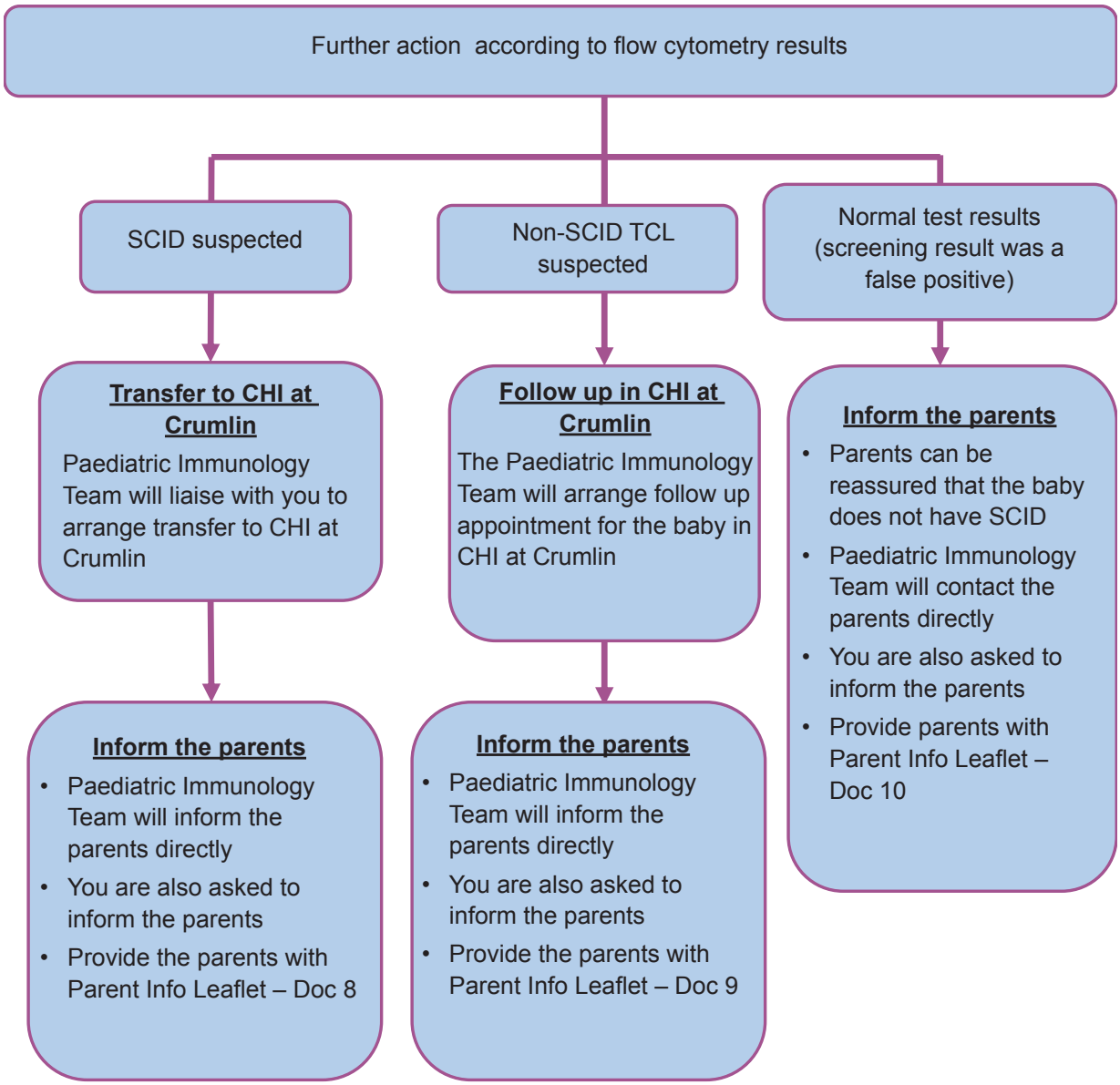

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Weekend practice – the maternity unit/ hospital/ paediatric service will not be asked to provide a weekend service for clinical review of babies who screen positive for SCID. However, you may be contacted over the weekend by the Consultant Paediatric Chemical Pathologist/ Consultant Clinical Biochemist on call for the National Newborn Bloodspot Screening Laboratory (NNBSL) such that you can contact the parent, communicate the screening result to them and arrange clinical evaluation and confirmatory testing for the next working day.

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Clinical evaluation form – baby who has screened positive for SCID

Patient details	Details of Neonatologist/Paediatrician conducting the evaluation
Patient name:	**Name:**
Address:	**Unit:**
DOB:	**Phone:**
MRN:	**Email:**
Sex: **Ethnicity:**	

Contact details	
Parent (1) name:	**Parent (2) name:**
Phone:	**Phone:**
Email:	**Email:**

Birth history

Gestation at Birth: /40 **Type of Delivery:** SVB ☐ LSCS ☐ Instrumental Delivery ☐

Birth weight: ____ g

Any complications during pregnancy/perinatal period e.g. blood transfusion, TPN, Gestational DM etc.
Yes ☐ No ☐ If Yes, give details:

Any maternal medication in pregnancy e.g. steroids, immunosuppressants, chemotherapy etc.?
Yes ☐ No ☐ If Yes, give details:

Family history

Any known family history of SCID/early childhood deaths: Yes ☐ No ☐
If Yes, give details:

Clinical progress since birth

Please detail any clinical concerns, in particular relating to feeding, weight gain/ loss, or possible infections:

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Current feeding

Exclusive breastfeeding ☐ Partial breastfeeding ☐ Formula feeding ☐ Other ☐

If other please specify: _____

Physical examination

Current weight: _____ **OFC:**_____ **HR:**_____ **RR:**_____ **BP:**_____ **Temperature:** _____

O2 saturations in room air:

Please detail any findings on physical examination (e.g. signs of infection, rash or respiratory distress):

Home circumstances (relevant to infection risk in babies who screen positive for SCID)

How many people live with you and the baby?

What kind of housing do you live in? (e.g. house, apartment, other)

Are there any sick family members/ contacts at home, including mild infectious illnesses:

Yes ☐ No ☐ If Yes, give details:

Take blood samples:

☐ **1 x 1ml EDTA blood sample for URGENT FBC** (to be analysed in local hospital laboratory)

☐ **1 x 1ml EDTA blood sample for URGENT flow cytometry - SCID screening lymphocyte subset -** Use the laboratory request form provided to you by the Clinical Liaison Nurse from the NNBSL. Request 'SCID Screen for Immunology' and send the fresh EDTA sample, through your local laboratory, at room temperature, without delay, e.g. by taxi, directly to the Immunology Lab, SJH, Dublin (sample to arrive Monday-Thursday, or no later than 12 noon on Friday).

Please phone the Paediatric Immunology team, CHI at Crumlin, immediately to discuss the findings of the clinical evaluation and management of the baby while confirmatory test results are awaited.

Contact information for Paediatric Immunology team, CHI at Crumlin:
Phone: 01 4096100 (CHI Crumlin Switchboard) & Bleep 8524/8426/8647/ Immunology registrar on call

Please email this form once completed to immunology@childrenshealthireland.ie

Signature _____ **Pin/Reg #:** _____ **Date:** dd/mm/yy **Time:** hh:mm

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Guidance for maternity hospitals/ units – Infection prevention and Control (IPC) measures for babies who have screened positive for SCID

Purpose of this leaflet

A baby born under the care of your maternity services has screened positive for severe combined immunodeficiency (SCID) through newborn bloodspot screening. This baby now needs urgent clinical review and confirmatory testing (flow cytometry) to determine whether they have SCID.

Until the results of confirmatory testing are available, babies who screen positive for SCID must be managed as potentially severely immunocompromised.

If the baby is clinically well and at home, they will need to return to the maternity hospital/ unit for clinical review and confirmatory testing. This leaflet outlines the infection prevention and control (IPC) precautions required when the baby attends hospital for clinical review and confirmatory testing.

Key principles

- Assume immunodeficiency until proven otherwise.
- Minimise exposure to infectious agents.
- Limit time in hospital and contact with others.
- Apply standard and enhanced infection control measures consistently.

Before the hospital visit

- Contact the parents to inform them of the screening result and schedule clinical review and confirmatory testing (see **Document 1 – Summary of guidance for maternity hospitals/ units – Follow up of a baby who has screened positive for SCID**). The clinical review should be scheduled **as soon as possible, ideally same day.**
- Arrange availability of a single room for clinical review of the baby.
- If available, a positive-pressure room or room with positive-pressure antechamber is preferable, but this is not essential and should not delay asking the baby to return for clinical review.
- Parents should be advised to bring the baby directly to the room where the clinical review will take place and should avoid busy waiting areas (e.g. Emergency Department/ OPD waiting rooms).
- Parents should be advised to bring the baby to the hospital in a car seat/ pram with a loose cover over same.

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- Parents should be advised exactly how best to come to designated room for clinical review and who to contact when they arrive or if they are having difficulty finding the location for clinical review.

Upon arrival

- Parents and baby should be brought directly to the assigned single room for clinical review.
- The door of the assigned room should be kept closed.
- Limit the number of staff interacting with the baby to the minimum necessary to undertake the clinical review and confirmatory testing. Blood tests should be undertaken in the same room to avoid mixing with other patients/ healthcare workers.
- Signs should be placed on the door "Protective Isolation, Strict Hand Hygiene Required, Staff and Visitor Restrictions in Place".

Standard precautions (all staff)

- Strict hand hygiene before and after contact with the baby.
- Use of aseptic technique for blood sampling.
- Clean and disinfect all equipment before use.

Personal Protective Equipment (PPE)

- Gloves and apron/gown for direct contact.
- Face mask for physical examination and procedures.

No contact with

- Staff who are unwell.
- Staff with recent exposure to communicable infections.

Handling and movement

- Keep the baby in their room for all care where possible.
- If movement is required (e.g. to phlebotomy), plan in advance to minimise exposure.
- Avoid contact with other patients.

Parents/guardians should

- Remain with the baby throughout the visit.

Blood sampling

The following blood samples are required:

1) **1ml EDTA for flow cytometry** – to be sent urgently by taxi to SJH Immunology laboratory, Dublin (sample to arrive Monday-Thursday, or no later than 12 midday on Friday)
2) **FBC** – for urgent analysis in local laboratory

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- Perform sampling promptly using aseptic technique.
- Ensure specimens are clearly labelled and transported promptly according to local laboratory protocols.

After the clinical review

After the clinical review, please contact the Paediatric Immunology consultant on call immediately to discuss the case and management required.

Contact details for Paediatric Immunology, CHI at Crumlin:

Phone: 01 4096100 (CHI Crumlin Switchboard) & Bleep 8524/8426/8647/ Immunology registrar on call

Further management will depend on whether the baby is well enough to go home or requires hospital admission.

- **If the baby is considered well enough to go home**, give the parents **Document 6 – Information for parents of babies at risk of SCID – What to do while waiting for your baby's specialist blood test result.** This document includes information on the IPC precautions parents need to keep their baby safe while confirmatory test results are awaited.
- **If the baby demonstrates clinical features that merit hospital admission**, admission should be arranged in your hospital/ unit following the infection control precautions outlined in the **Document 7 – IPC measures for maternity hospitals/ units – Baby with suspected or confirmed SCID** pending the results of the confirmatory testing.

  If a suitable cot/ cubicle is not available in your unit at the time, and hospital admission is deemed necessary, liaise with the Paediatric Immunology team in CHI at Crumlin to explore alternative arrangements.

  A treatment plan should be made in conjunction with the Paediatric Immunology team.

Environmental cleaning

After the clinical review:

- clean and disinfect examination surfaces, cots and chairs and any reusable equipment after use
- follow local IPC policies for cleaning clinical areas used by the infant.

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Detailed information to support maternity hospitals/ units communicating SCID screen positive result to parents

Purpose of this leaflet

A baby born under the care of your maternity services has screened positive for severe combined immunodeficiency (SCID) through newborn bloodspot screening. This leaflet to support you in communicating a positive newborn screening result for SCID to parents over the phone, is informed by recent engagement with parents of babies who screened positive for other conditions, and healthcare professionals who have delivered screen positive results for other conditions.

Of critical note: The screening result is not diagnostic. A positive screening result indicates only that a baby is at increased risk of SCID (or another condition affecting their immune system). This baby now needs urgent confirmatory testing (flow cytometry) to determine whether they have SCID.

You are asked to:

- locate the baby and communicate the screening result and next steps to the parents
- arrange prompt clinical review of the baby, confirmatory testing (flow cytometry), and paediatric immunology input.

Before phoning the parent about the screening result it may be helpful to:

- **Read this document in full** – it contains practical tips to help guide you in communicating the screening result and next steps to parents.
- **Read Document 5 – Information for parents of babies at risk of SCID** – this contains key information for parents in accessible language.
- **Ensure the clinical review is arranged and that you have all the details to hand –** date (ideally same day)/ time/ location/ what hospital entrance to attend/ who parents can contact if they have any difficulty finding the location for the clinical evaluation.

The phone call

Try to ensure that you are in a quiet environment and will not be interrupted during the phone call.

Key information to tell parents

- ✓ Your baby has had a positive screening test result for SCID.
- ✓ This is NOT a diagnosis – at this stage we do not know whether your baby has SCID or not, so a blood test is needed to find that out.
- ✓ Explain what SCID is using accessible language (see **Document 5 – Information for parents of babies at risk of SCID** for simple language you can use to explain what SCID is).

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- ✓ Most babies who screen positive for SCID will not have the condition, but for those who do, early treatment is essential to improve outcomes.
- ✓ There is also a chance that your baby may have another less serious condition that affects the immune system (non-SCID TCL), or the blood test may show that they do not have SCID or non-SCID TCL (false positive screen).
- ✓ If your baby does have SCID, this is a treatable condition, and their outcomes can be very good.
- ✓ The baby is not in any immediate danger but does need to be seen urgently.
- ✓ Give information on clinical evaluation – date (ideally same day), time, where to bring the baby.
- ✓ Infection prevention and control (IPC) – Discuss with parent how they intend to travel to the hospital and give them advice on how to keep infection risk as low as possible. Advise the parents that more information on keeping infection risk low is provided in the parent information leaflet you will email to them after the call.
- ✓ Ask whether the parents have any questions.
- ✓ Tell the parents that you will email them the appointment details (date/ time/ location etc.) and a parent information leaflet after the call and ask them for an email address to send this information to.

After the phone call

Send parents a follow up electronic communication with:

1) details of the clinical evaluation (date/ time/location etc.)

   and

2) **Document 5 – Information for parents of babies at risk of SCID**

Parental feedback on receiving screen positive results

Delivering a screen positive result to parents is inherently challenging. The National Newborn Bloodspot Screening Programme (NNBSP) has recently engaged with parents and healthcare professionals to understand their experience of communicating positive newborn screening results, before a definitive diagnosis has been made.

Parents cited emotions of shock, worry, fear, upset and overwhelm on hearing about a screen positive result for their baby. They noted how challenging it can be to take in and understand the information they are being told, particularly in the busy postnatal period.

Parents stressed the importance of kind, empathic communication, and being clearly informed of key information including:

- the screening result is **not** a diagnosis, and their baby **is not in** imminent danger
- even if their baby is found to have the condition, effective treatments are available and their baby can be supported to achieve good outcomes.

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Healthcare professionals told us that they generally feel confident communicating screen positive results to parents, but would like some further support and guidance, particularly for very rare conditions. We hope this guidance document is useful in this regard.

Please scan the QR code to give brief feedback on whether you found this document useful and how we can improve it.

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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.

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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.

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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.

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National Newborn Bloodspot Screening Programme

Infection Prevention and Control (IPC) measures for maternity hospitals/ units – Baby with suspected or confirmed SCID

1. Purpose of this leaflet

A baby born under the care of your maternity services has screened positive for severe combined immunodeficiency (SCID) through newborn bloodspot screening.

This baby has had an urgent clinical review and confirmatory testing (flow cytometry) to determine whether they have SCID.

Following clinical review, there is strong clinical suspicion that this baby has SCID and/ or the results of confirmatory testing (flow cytometry) suggest a diagnosis of SCID.

This leaflet outlines the infection prevention and control (IPC) precautions required to minimise the risk of infection in infants with suspected or confirmed SCID while admitted under your care and awaiting transfer to CHI at Crumlin.

2. Scope

These precautions apply to all healthcare workers, caregivers, visitors, and ancillary staff involved in the care of an infant with suspected or confirmed SCID in in-patient hospital settings (NICU, PICU, paediatric ward).

3. Patient risk summary

Infants with SCID lack functional T-cells. As such, they are unable to mount effective immune responses and are highly vulnerable to viral, bacterial, fungal, and protozoal infections.

They may not show typical signs of infection (e.g. fever).

All infections should be considered potentially life-threatening.

4. Isolation precautions

4.1 Room requirements

All babies with suspected or confirmed SCID should be cared for in single patient rooms only.

They should be cared for in protective (reverse) isolation.

Where available, a positive-pressure room or a neutral pressure room with positive-pressure anteroom is preferable. The room door should always remain closed.

4.2 Signage

The room should be labelled with clear signage indicating “Protective Isolation, Strict Hand Hygiene Required, Staff and Visitor Restrictions in Place”

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5. Hand hygiene

Mandatory hand hygiene before and after all patient contact is essential.

Staff and visitors should wash their hands with alcohol-based hand gel or soap and water (soap and water are mandatory if hands are visibly soiled) before entering the room.

Hand hygiene required:

- before entering room
- before touching patient or patient environment
- after glove removal
- before exiting room.

6. Personal protective equipment (PPE)

6.1 Healthcare workers

- Gloves: Required for all toileting, application of creams, and for any intravenous procedures.
- Gown: Required for all intravenous access.
- Surgical mask: Required for all staff at all times.

6.2 Visitors and parents

- Visitors limited to parents/ guardians and two nominated healthy adult visitors.
- Must perform hand hygiene on entry and exit, before patient contact and after removal of gloves.
- Parents must wear gown, but do not need to wear face mask.
- Other visitors must wear mask and gown as instructed.
- Gloves must be worn when applying creams/ ointments and when changing nappy.
- Kissing of the baby's face and/ or hands is strongly discouraged. It is important that parents are encouraged to bond with their baby; parents can kiss the baby as long as they avoid the face and hands.

Parents/ nominated adult visitors should not enter the room if they have the following symptoms suggestive of a contagious infection:

- respiratory symptoms (e.g. cough, coryza, sneezing)
- fever
- diarrhoea or vomiting
- rash
- cold sores

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Parents/ nominated adult visitors should not enter the room if they have recent exposure to communicable diseases such as measles, varicella (chickenpox or shingles), RSV, influenza or COVID-19 infection, without discussing with the nursing and medical team beforehand.

7. Environmental controls

7.1 Patient environment

Every effort should be made to keep the patient's room clean with regular use of hospital-approved disinfectants.

Clutter in the room should be kept to a minimum.

The baby's clothes, bedding and soft toys should be washed daily at a minimum temperature of 60°C.

The room should have dedicated medical equipment (stethoscope, thermometer, BP cuff).

Only hospital-approved, easily cleanable toys should be in the room.

The toys should be cleaned and disinfected daily.

No stuffed animals or porous materials should be allowed in the infant's cot.

8. Feeding and nutrition

8.1 Breastfeeding

Breastfeeding should only be permitted if maternal cytomegalovirus (CMV) status is known and breastfeeding is deemed safe by the Paediatric Immunology team.

Pasteurised expressed breast milk may be used if indicated.

8.2 Formula feeding

If formula feeding, use sterile or ready-to-feed formula.

Strict aseptic technique is required for formula preparation and feeding.

9. Procedures and clinical care

For procedures and clinical care:

- use aseptic technique for all procedures
- minimise invasive procedures where possible
- avoid suppositories or enemas.

10. Medications, prophylaxis and blood products

When administering medications, prophylaxis and blood products:

- Administer antimicrobial prophylaxis and immunoglobulin replacement therapy as directed by Paediatric Immunology team.

- Blood products, if necessary, should be CMV-negative and irradiated.
- No vaccines should be given to the baby prior to definitive treatment (e.g. HSCT).
- Nirsevimab is indicated for the baby during RSV season.
- Avoid exposure to individuals who have received live nasal-influenza vaccine.

11. Staff health requirements

Staff caring for the baby with suspected or confirmed SCID must be:

- Free of infectious symptoms, e.g. cough, coryza, fever, rash, cold sores, diarrhoea.
- Up-to-date with recommended vaccinations (per institutional policy).
- Staff recently exposed to communicable diseases should not provide care until cleared by Occupational Health.
- Staff should not be co-assigned to care for children/ infants with active contagious infection (e.g. RSV, influenza, adenovirus).

12. Transport and diagnostic procedures

The baby should be kept isolated in the room to the greatest possible extent.

If imaging is necessary, portable x-ray/ ultrasound/ echocardiogram should be utilised if possible.

If transport to the radiology department for other imaging modalities is necessary or if transport to other parts of the hospital is needed (e.g. theatre, PICU), the infant should be transported in an incubator to reduce the risk of exposure to droplet/ airborne infections.

The receiving department should be notified in advance that protective isolation is needed. Every effort should be made to minimise waiting time in shared areas.

13. Family education

Parents and nominated visitors should receive education on:

- importance of infection prevention
- hand hygiene and PPE use
- visitor restrictions
- early signs of infection and when to alert staff.

14. Review and escalation

The above precautions are to remain in place until:

- SCID is excluded

  OR

- immune reconstitution occurs post-definitive treatment (e.g. post-HSCT).

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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)

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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.

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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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Babies with normal test results for SCID - information for parents

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 were normal and showed that your baby **does not** have SCID.

This is very good news.

Why did the screening test show my baby was 'at risk of SCID' when they do not have it?

This was a false positive screening result. This is when the screening test suggests that your baby is at increased risk of a condition, but further testing shows that they **do not** have the condition.

False positives happen in all screening programmes. They happen because screening tests are not perfect.

That is why all babies who have a positive screening test need to have further tests. This is to find out whether they have the condition.

Your baby had a false positive screening result. Further testing has shown that they do not have SCID.

For more information on false positives see www2.hse.ie/conditions/heel-prick-screening/results/

What happens next?

Your baby does not need any further tests.

You were advised to take extra care to reduce the risk of infection while waiting for your baby's test results. This included keeping your baby at home and away from any sick family members or friends.

Now that we have the test result, we know that your baby **does not** have SCID. Your baby is not at higher risk of infection compared to any other baby.

This means that you can stop taking extra precautions. Your baby can continue with normal activities and feeding.

For all babies, we recommend you visit the HSE's mychild.ie for advice on caring for your child as they grow.

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I still have questions, who can I ask?

A screen positive result can be very worrying for parents.

Even though further blood tests have shown that your baby **does not** have SCID, you may still have some questions or concerns.

A member of the Paediatric Immunology team in CHI at Crumlin will contact you in the coming days. They will discuss your baby's test results and answer any questions you may have.

As with any healthy child, seek advice from your GP or public health nurse if:

- your baby becomes unwell, or
- you have any concerns about your baby's feeding or development.

For more information on your baby's health and development and supports for parents, please visit the HSE's mychild.ie

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Severe combined immunodeficiency (SCID) – Technical information for healthcare professionals

What is SCID?

Severe combined immunodeficiency (SCID) is the most severe form of primary immunodeficiency. It is an inborn error of immunity characterised by an intrinsic defect in the patient's hematopoietic stem cells (HSCs) that prevents their differentiation into phenotypically and functionally mature T-cells. SCID may also have defects in B-cell differentiation and/ or function and/ or natural killer (NK)-cell differentiation.

It is called a "combined" immunodeficiency, since patients have a combined impairment of both their T-cell mediated cellular immunity and their B-cell antibody mediated humoral immunity.

It is termed "severe" since, without treatment, patients with this condition typically do not survive longer than one year, succumbing either to severe recalcitrant infection (including from live vaccination), malignancy, and/ or complications from immune dysregulation.

Patients are typically asymptomatic at birth, and most patients do not have a positive family history of the condition.

What causes SCID?

SCID can be caused by a pathogenic variant in one of at least twenty different genes.

Inheritance is typically either autosomal or X-linked recessive.

What is the incidence of SCID?

The incidence of SCID varies widely across geographic locations and within certain populations and is likely to be under-reported in the absence of population-based screening, as babies may not survive to diagnosis.

The estimated incidence of SCID in Ireland is approximately 1 in 40,000 live births.[1]

How is SCID treated?

Definitive treatment of SCID requires establishing a HSC population intrinsically capable of generating T-cells, either by allogeneic haematopoietic stem cell transplantation (HSCT) or by transplantation with gene-corrected autologous HSCs.

Early detection (including through newborn screening) and treatment of SCID is associated with improved clinical outcomes and survival.

1 Burns, H., Collins, A., Marsden, P., Flood, T.J., Slatter, M.A., Booth, C., et al. (2021). Severe Combined Immunodeficiency (SCID) - the Irish Experience. *Journal of Clinical Immunology, 41(8),* 1950-1953.

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How is newborn screening for SCID undertaken?

Newborn screening for SCID was introduced in Ireland in 2026.

Newborn screening for SCID is undertaken through quantification of T-cell receptor excision circles (TRECs). TRECs are small, circular DNA fragments produced during normal T-cell development in the thymus. They serve as a surrogate marker of naïve T-cell production.

TRECs can be quantified on the dried bloodspot (DBS) sample using real-time quantitative polymerase chain reaction (qPCR). Low or absent TRECs are indicative of T-cell lymphopenia (TCL) and may indicate a diagnosis of SCID.

While SCID is the target of newborn bloodspot screening, low TRECs can also indicate non-SCID TCL, a clinically heterogeneous group with a diverse range of underlying causes.

Low TRECs may be associated with:

Primary immunodeficiencies

- SCID **– this is the most clinically serious potential outcome and is the target of the screening programme.**
- Leaky SCID/ combined immunodeficiency.
- Other non-SCID T-cell lymphopenias.

Secondary or transient causes

- Prematurity.
- Congenital heart disease.
- Genetic syndromes (e.g. 22q11 deletion).
- Perinatal stress or severe illness.

How good is the screening test at detecting SCID?

The positive predictive value (PPV) of TREC based newborn screening for SCID (excluding other causes of TCL) ranges from 0.80% to 20.00%.[2]

Most babies who screen positive will not ultimately have a diagnosis of SCID, but for those who do, prompt diagnosis and treatment is essential for optimal clinical outcomes.

What happens if confirmatory testing indicates a diagnosis of SCID or non-SCID TCL?

Where confirmatory testing (flow cytometry) indicates a potential SCID or non-SCID TCL, the baby will be transferred to the care of the Paediatric Immunology team, Children's Health Ireland (CHI) at Crumlin.

2 https://www.hiqa.ie/reports-and-publications/health-technology-assessment/hta-addition-severe-combined-immunodeficiency

ADA-SCID /SCID Newborn Screening Follow-up Request Form

National Newborn Bloodspot Screening (NNBS) CHI Temple St, DPLM (CODE:563 LF-NNS-0146 Edition 3)

ADA SCID/SCID Newborn Screening Follow-Up Request Form

Sample taker please complete:	
Maternity/Paediatric Hospital	
Baby Hospital No / MRN	
Surname	
First Name	
Date of Birth (DD-MM-YYYY)	
Gender M/F	
Date & Time of test	
Referring Paediatrician (Print Name)	
Contact Number	

Suspected Condition
ADA SCID/SCID on Newborn Screen

Address for Test Referral
Immunology Laboratory, St James' Hospital, James' Street, Dublin 8 **Eircode D08 NHY1**

Sample Type	Sample Requirements
1ml EDTA SCID/**2ml** EDTA ADA-SCID (Fresh whole blood ambient temperature) **DO NOT FREEZE**	Send immediately (taxi) to Immunology Dept, St James' Hospital Dublin D08 NHY1
Investigation Required	
ADA SCID (TBNK, Naïve and Activated T cells ADA Enzyme and Metabolite Screen)	
SCID (TBNK, Naïve and Activated T cells)	

SJH contact details for sample delivery:
Mon – Fri 8am - 5 pm: Contact the St James' switch at 01-4103000 and ask for Immunology On-call Consultant.

Addresses for Reporting
NNBSL, CHI Temple St, Dept of Paediatric Laboratory Medicine , Email info.newbornscreening@childrenshealthireland.ie contact no 01-892 1804
Immunology department, CHI Crumlin email immunology@childrenshealthireland.ie contact no 01 409 6893

Receipt of Sample in St James	
Date and Time Received	
Sufficient for Flow Testing (Y / N)	
Sufficient for ADA Enzyme and Metabolite Screen (Y / N)	

Comments

NOTE TO REFERRING LABORATORY: Please use this request form ONLY for Newborn ADA-SCID/SCID Screening Follow-up

SCID/ADA-SCID Laboratory Request Form for Flow Cytometry

Appendix