

## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### Procedure Responsibilities and Authorisation

<b>Department Responsible for Procedure</b>	Neonatal Intensive Care Unit (NICU)
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<b>Target Audience</b>	Health care professionals caring for newborns
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### Procedure Review History

Version	Updated by	Date Updated	Description of Changes
1	Nadia Cooper	October 2016	First version
2	Richard Pagdanganan	November 2019	Due for review
3	Hayley Clark	November 2022	3-yearly review

## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

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## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### 1. Overview

#### 1.1 Purpose

To ensure safe and accurate collection of the newborn metabolic screening test, in the NICU environment, in compliance with the Ministry of Health.

The test screens for 20 rare but potentially serious conditions.

The current conditions screened for include:

- amino acid disorders (e.g., phenylketonuria (PKU) and maple syrup urine disease)
- fatty acid oxidation disorders (e.g., MCAD)
- congenital hypothyroidism
- cystic fibrosis
- congenital adrenal hyperplasia
- galactosaemia
- biotinidase deficiency
- severe combined immunodeficiency (SCID)

#### 1.2 Scope

Health care professionals caring for newborns within the hospital and community including:

- Registered Nurse (RN)
- Enrolled Nurse (EN) under the direction and delegation of an RN
- Midwife/Lead Maternity Carer (LMC)
- Neonatal Nurse Practitioner (NNP)/Doctor

Allied Health for additional roles: Department Receptionist

#### 1.3 Patient / client group

All Newborn infants admitted to Te Whatu Ora Waikato facilities.

#### 1.4 Exceptions / contraindications

##### Parents decline screening

If parents have been well informed and declined newborn screening, fill in the testing card with details, document on it that screening is declined and send the card without the blood. Ensure that parents are aware that testing can be completed later if they change their mind, though ideally between 48-72 hours after birth, and who to contact in this instance.

Document discussion in clinical notes and inform medical team.

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## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### 1.5 Definitions

<b>Guthrie</b>	Alternative name for the Newborn Metabolic Screening (preferred). Guthrie's test refers to the original inventor of the newborn metabolic screening Robert Guthrie.
<b>Metabolic disease</b>	A group of disorders where any of a variety of metabolic pathways can malfunction, at any point in the pathway, resulting in disrupted protein delivery and production and preventing normal body function.
<b>National Screening Unit (NSU):</b>	The governing and regulating body for newborn metabolic screening in New Zealand which functions under the Ministry of Health
<b>Newborn metabolic Screening-NMS</b>	A New Zealand health initiative to ensure early diagnosis of newborn with a range of metabolic diseases and SCID This promotes early treatment and management for rare, but treatable, diseases and prevents and/or minimises morbidities and mortality.
<b>NTC</b>	Newborn testing card
<b>PKU</b>	Alternative name for the Newborn Metabolic Screening – (preferred) Phenylketonuria is an inborn error of metabolism that results in decreased metabolism of the amino acid phenylalanine. Untreated, PKU can lead to intellectual disability, seizures, behavioural problems, and mental disorders. It was the first metabolic disorder able to be screened for.
<b>SCID</b>	Severe combined immune deficiency

### 1.6 Roles and Responsibilities

#### RN/EN/LMC/Midwife:

- Obtain informed consent.
- Collect samples and ensure correct details are documented on the test card.
- Complete relevant documentation.

#### Receptionist - NICU:

- Receptionist enter the details in the NICU PKU book and fill in all available details on the newborn testing card (NTC) stamp 'VAN84'
- NTCs are given to the bedside nurse or put at the bedside on the morning the sample is due.
- Completed and dried cards are collected from the office collection bag. Details are checked including collection date in PKU book. Cards are sent to the laboratory using the Lamson.

## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### 2. Clinical Management

#### 2.1 Competency required

- Registered Nurse/Midwife who has completed education on appropriate sample collection
- Enrolled Nurse who is under the direction and delegation of an RN and has completed education on appropriate sample collection

#### 2.2 Equipment

- NSU screening pamphlet “Your Newborn Baby’s Blood Test.” (See section 2.1 Associated Documents for link).
- Blood sample collection equipment: refer to NICU service specific nursing procedure
- [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352)
- Newborn test card (NTC) (beige for postnatal, blue for NICU).
- Documentation:
  - Receptionist to fill in the initial details in the NICU specific NMS book.
  - Nurses to document date/time of collection in the following locations: Clinical notes, Neonatal Problem Sheet (green), NICU Admission Form (yellow), Well Child Book, NICU PKU Book.

#### 2.3 Procedure

##### 2.3.1 Consent

Newborn metabolic screening requires informed verbal consent from a parent/guardian prior to testing. Nurses are responsible for consenting parents in NICU.

Generally an LMC will have discussed the test with the parents in antenatal care, unless in the case of preterm delivery. However, provide parents with the “Your Newborn Baby’s Blood Test” NSU pamphlet and clarify their understanding.

There are two parts to consent:

- a) Parents consenting for their baby to be screened for metabolic diseases
- b) Parents consenting for the screening card to be stored or requesting for residual blood samples to be returned to them.

When English is a second language, assess whether an interpreter is required to ensure consent is sufficiently informed. See [Interpreters and Translation](#) (Ref. 0137)

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### 2.3.2 Once verbal consent has been obtained, document in the infant's clinical notes.

Some parents will experience anxiety waiting for results or be fearful of positive results. Ensure that parents are well informed of the routine nature of this screening process and the rarity of these disorders, as well as the benefits of early recognition/treatment.

### 2.3.3 Parent Information

New Zealand was one of the earliest countries to implement Newborn metabolic screening in 1969. New Zealand Newborn Metabolic screening tests for a range of 28 diseases and disorders which are rare but can be well-managed if detected early and treatment begins promptly. All these conditions are life-long and many, without early recognition have extensive morbidities and can cause death.

Testing is offered to all families both in hospital and in the community and is not based on specific risk. Collection is recommended between 48-72 hours after birth, as the newborn metabolic system takes time to reach detectable abnormal levels of substances tested for. Beyond 72 hours some metabolic diseases, if present, may have already caused consequences for the infant. Therefore, the recommended timing window allows for the earliest accurate detection to prevent morbidities and mortality.

Normal metabolic adaptation is based on the infant receiving milk feeds. If the infant has not received adequate enteral milk prior to the test being performed, this may need to be repeated when the infant reaches full feeds (e.g. Neonatal encephalopathy or surgical infants with clinical concerns).

Please see "Your Newborn Baby's Blood Test" NSU pamphlet for more information or the NSU website.

### 2.3.4 Storage or return of residual sample:

**Storage:** With parental consent residual samples will be stored indefinitely in a secure facility. Stored blood spots may be used for:-

- Further investigation if baby develops a disorder but initially tested negative.
- To improve the screening programme.
- For research approved by an ethics committee and Ministry of Health.
- To investigate a death or illness within the family.

**Return:** If parents wish for the residual samples to be returned then complete a "request for return" form including parent/guardian signed consent and address for return and send this with the test card. The lab will ensure residual samples are returned.

The form for request for returned samples can be found here:

<https://www.nsu.govt.nz/system/files/resources/request-form-return-of-card-final.pdf>

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### 2.3.5 Preterm infants:

Due to functional immaturity preterm infants metabolic screening will commonly have positive screening with one or more results outside of normal parameters. This is a normal physiological occurrence. Because of this:

- Preterm infants <1500g require repeat screening at 2 weeks of age.
- Preterm infants <1000g require a third screening at 4 weeks of age.

Importantly: When consenting parents of premature infants reassure them of the normality of a positive screen in this group and why. Obtain consent for repeat screening.

### Collection

Collection must occur as soon as possible after 48 hours from birth but prior to 72 hours, as recommended above.

Receptionists will place the cards at the bedside for each baby when it is due for the nurse to collect the sample. This includes repeat samples. NICU screening cards are blue.

- Please see NSU metabolic screening guidelines for details on collection ([https://www.nsu.govt.nz/system/files/page/metabolic\\_screening\\_guidelines\\_final\\_february\\_2010.pdf](https://www.nsu.govt.nz/system/files/page/metabolic_screening_guidelines_final_february_2010.pdf)) and NICU service specific nursing procedure: [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352)

See Appendix A for safe site selection for neonatal heel prick sampling.

### Points to remember:

- Enteral feeding is not a requirement for a valid sample, but a repeat sample may be required in an infant who is not fully fed.
- Before collecting the blood sample check all information sections are filled in, consent has been obtained and the patient identifiers on the card match those on the patient (NHI, name and date of birth).
- Take care not to touch the blood spot area before collecting the sample.
- All four spots on the test card must be filled to the edges and soak through to the back of the card. Blood must be applied only to ONE side of the testing card.
- Blood may be dropped directly onto the circles from a syringe. The use of capillary tubes is not recommended.
- DO NOT layer new blood on dried blood.
- Dry the card horizontally at the bedside for 1-3 hours (use card flap to make a stand). Blood is no longer red when dry.
- LMC details MUST be provided to ensure follow-up in the community for discharged babies.

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- If parents request for return of residual samples ensure appropriate forms are completed, as per NSU website, and send with the sample.
- Send as soon as possible after drying to avoid delay in testing.
- Complete required documentation. (See Appendix B for an example of a completed NICU “blue” card).

### 2.3.6 Sending

All test cards must be sent as soon as possible once they have dried.

Receptionists ensure all details are filled in and the testing card is recorded in the red PKU book. Testing cards are to be placed in an envelope making sure not to fold the testing cards. The purple address sticker is placed on the envelope and sent to the laboratory via the Lamson no later than 0930 hours.

All posted samples to be sent to:

Newborn Metabolic Screening Programme LabPLUS  
PO Box 872  
Auckland 1140

### Following up

Results can come back electronically in CWS

A **negative screen** means that results are within normal parameters. This should be communicated to the parents.

An **unsuitable sample** means that there was inadequate blood or inappropriate timing to obtain accurate results. A repeat screening will be required in this situation. Parental verbal consent must be obtained prior to repeat screening. Complete repeat screening as soon as possible.

A **positive screen** is usually phoned to the neonatal unit or lead clinician. It means that one or more results are outside of normal parameters. If the infant is still admitted at Waikato hospital inform the NNP/CNS/Registrar, to review and discuss the results with the parents, document in the notes, and inform LMC. If the infant has been discharged contact the LMC with the results for communication to the parents.

## 2.4 Potential Complications

- **False Negative results:** The screening process is not diagnostic and false negative results are possible. It is essential that clinicians do not ignore clinical symptoms based on a negative result.
- **Heel Prick care:** Please see the NICU service specific nursing procedure [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352) to ensure correct sample collection and minimise bruising and adverse outcomes of heel prick sample collection.

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## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### 3. Audit

#### 3.1 Indicators

- All babies have Newborn Metabolic Screening within 72 hours after birth (unless declined by a parent/caregiver)
- There is evidence of informed consent for every test taken
- The sample cards and PKU book are completed in full for every infant

### 4. Evidence Base

#### 4.1 Associated Documents

- Code of Health and Disability Services Consumer' Rights Regulations. Health and Disability Commissioner. Retrieved from: <https://www.hdc.org.nz/media/2829/you-have-rights-easy-read-version.pdf>
- Link for documents and information pamphlets from NSU: [www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/information](http://www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/information)
- Ministry of Health eLearning Module; Best Practice – Newborn Metabolic Blood Spot Collection. <https://learnonline.health.nz/enrol/index.php?id=436>
- Ministry of Health eLearning Module; Newborn Metabolic Screening Programme (NMSP). <https://learnonline.health.nz/enrol/index.php?id=163>
- NSU website for national recommendations/requirements and further information: <https://www.nsu.govt.nz/health-professionals/newborn-metabolic-screening-programme/procedures-guidelines-and-reports-0-0>
- [Heel Prick for Blood Sampling in Neonates](#) (Ref. 4352)

#### 4.2 Bibliography

- Ministry of Health: National Screening Unit. (2017). Guidelines for practitioners providing services within the Newborn Metabolic Screening programme in New Zealand. Retrieved on October 18, 2019 from: [https://www.nsu.govt.nz/system/files/page/metabolic\\_screening\\_guidelines\\_final\\_february\\_2010.pdf](https://www.nsu.govt.nz/system/files/page/metabolic_screening_guidelines_final_february_2010.pdf)
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have the best start in life. Retrieved on October 15, 2019 from

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## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### Appendix A – Safe sites for neonatal heel prick for sampling

Need to label safe areas where arrows are pointing



## Newborn Metabolic Screening in the Newborn Intensive Care Unit (NICU)

### Appendix B – Example of Blue NICU Test Card Completed

**Collected sample filling each of the 4 circles to the black line**

**Neonatal details written DO NOT cover this area with a sticker.**

**Maternal and neonatal details. A full sticker can be used in this section**

**Midwife/LMC details. Must be provided to ensure follow-up in the community**

**Neonatal delivery and test collection time details.**

**Note:**

- Test within **48-72** hours from birth
- Infant <1500g requires repeat testing

**LAB USE ONLY DO NOT COVER** NHI # ABC123  
BABY SURNAME Doe

**LAB USE ONLY DO NOT COVER**

**BABY INFORMATION - FILL OUT OR USE LABEL**  
NHI Number ABC123  
Surname DOE  
First Name Baby of Jane  
Sex M

**MOTHER'S INFORMATION - if not on label**  
Surname DOE  
First Name Jane

**REPORT TO** VAND84  
Name / Unit

**COPY TO (LMC OR WELL CHILD PROVIDER)**  
Name Julia Midwife  
Address 123 Delivery Place

Hospital Waikato Ethnicity NZM  
Birth time 00:23 Birth date 01/02/2021  
Gestational age 29 wk Birth Wt. (g) 1400  
Collection time 1330 Collection date 03/02/2021  
Select  1st  2nd  3rd sample Further sample to come  Y  N