Health New Zealand

Lakes

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TITLE: Newborn Metabolic Screening

Contents

1.	Statement/Purpose	1
2.	Scope	2
3.	Definitions	2
4.	Procedure	2
5.	Low Birth Weight and Sick Babies	5
6.	Babies Who Have Received Blood Transfusion	5
7.	Sending Samples	6
8.	Results	6
9.	When Consent is Not Given for Testing	6
	Request for Return of the NBMS Card	
11.	Further Staff Education	7
12.	Related Documentation	7
13.	References	7
14.	Audit	8

1. Statement/Purpose

Newborn Metabolic Screening (NBMS) of every baby born in New Zealand is strongly recommended by the Ministry of Health (MOH) to identify babies with rare metabolic disorders as early as possible, to enable early treatment and reduce associated morbidity and mortality.

This procedure seeks to assist staff to ensure;

- The parent(s)/guardian(s) of each baby born in a Lakes facility is given information and an
 opportunity to make an informed decision about whether to have their infant's blood tested for
 metabolic disorders included as part of the screening test.
- When parent/guardian consent is given, timely and safe screening occurs
- Lakes meets the National Screening Unit (NSU) Monitoring Indicators for NBMS:

○ Coverage: ≥ 99%	of babies born nationally and within each of Maori, Pacific,
o Sample: ≥ 95%	Asian and Other population groups are screened of first samples are taken between the optimal time of 24 and 48
	hours after birth and before 72 hours
 Quality: ≥ 99% 	of blood spot samples received are of satisfactory quality
\circ Delivery: ≥ 95%	of samples are received by the laboratory within four calendar days of being taken

Key Word(s): WCF, WH, Maternity, Newborn, Metabolic, Screening						
EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 1 of 8		

Lakes

2. Scope

All Te Whatu Ora Lakes employed Midwives and Nurses working in the Maternity Service (Rotorua and Taupo Hospitals) and Special Care Baby Unit (SCBU), all Paediatricians and Lead Maternity Carer (LMC) Access Agreement Holders.

All administrative staff working in the Maternity Service (Rotorua and Taupo Hospitals).

3. Definitions

Newborn	A blood test using a sample of blood taken from the heel of a newborn
Metabolic	baby optimally between 24 - 48 hours of age and before 72 hours. It tests
Screening	for 23 metabolic disorders and other disorders:
	Ansier seid die ondere (44 die ondere is de die e DKU and MOUD)

- (also known as 'Guthrie, 'PKU' or 'blood spot' test)
- Amino acid disorders (14 disorders, including PKU and MSUD)
- Fatty acid oxidation disorders (9 disorders)
- Others:
- Congenital hypothyroidism
- Cystic fibrosis
- Congenital adrenal hyperplasia
- Galactosaemia
- Biotinidase deficiency
- Severe combined immunodeficiencies

4. Procedure

Ensure the newborn is at least $\underline{24}$ hours old. The optimum age for testing is between 24 - 48 hours and before 72 hours of age.

a) Informed Consent

- Parent/guardian has been given information leaflet about NBMS <u>('Your newborn baby's blood test', MOH, Code HE2310</u>).
- They understand the reason for screening and how screening will be done (use an interpreter if required)
- The possible results, how results will be communicated and any next steps
- Storage, return or possible future use of residual sample has been explained
- Screening is voluntary and parent/guardian may decline on their baby's behalf

Key Word(s): WCF, WH, Maternity, Newborn, Metabolic, Screening						
EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 2 of 8		

b) Complete Details on Card

- Fill in the details on the card prior to and at the time of taking the sample
- Complete all fields and ensure a contact telephone number for the LMC is provided in case the laboratory requires urgent contact for positive results

c) Gather Equipment

- gloves
- water and gauze to cleanse foot (if required)
- gauze
- plaster with easy to remove adhesive
- approved lancet for newborn blood sample collection
- completed metabolic screening (blood spot) card
- prescribed sucrose 0.5 1.0ml orally (if unable to be breast or bottle fed or have skin to skin during the procedure)

d) Ensure Newborn is Warm and Comfortable

- Encourage parent/guardian to cuddle newborn, skin to skin or bottle/breast feeding is ideal but not essential
- Ensure newborn is in a position where his/her foot is accessible ideally hanging down to encourage blood flow
- Ensure the newborns' foot is warm for good perfusion using booties, socks, blankets etc. if necessary

e) Infection Control Precautions

- Wash hands and put on gloves. This is not a sterile procedure, however universal infection control precautions should be taken to prevent sample contamination and to protect both the newborn and the sample collector
- Make sure the newborn's foot is clean and dry. If necessary clean foot with a small amount of water and clean gauze, allow to dry completely

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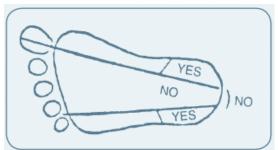
Key Word(s): WCF, WH, Maternity, Newborn, Metabolic, Screening							
EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 3 of 8			

Health New Zealand

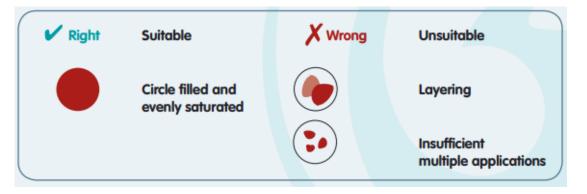
Lakes

f) Take the Sample

- Hold the newborn's heel with the non-dominant hand as shown in the picture (right)
- Choose a site free from previous sampling attempts
- Place lancet against the heel in one of the areas shown in the diagram (right), and activate.
- Wait up to 15 seconds for capillary blood to flow
- Wipe off the first drop
- Allow blood to fill each spot by natural flow
- Fill from the same side of the card, allowing blood to seep through
- Ensure the spot is filled
- Do not layer spots







Note: Avoid touching the collection paper on the blood spot card with the newborn's foot or the collectors hand, to prevent contamination and another sample needing to be taken.

- If a second puncture is required, select a new site on a different part of the foot
- Apply gentle pressure to puncture site(s) with clean gauze, apply a plaster if required

g) Handling the Completed Card

- The card must be dried horizontally in the designated place on the ward for 1 ½ 2 hours out of direct sunlight (use card flaps as a stand see back of card for instructions)
- When the blood is dry (no longer bright red), follow the instructions on the back of the card to wrap the card flaps over to cover the spots to protect them

h) Documentation

Document that NBMS has been completed;

- in the Well Child Book
- on the Newborn Record
- in the SCBU green book and discharge form

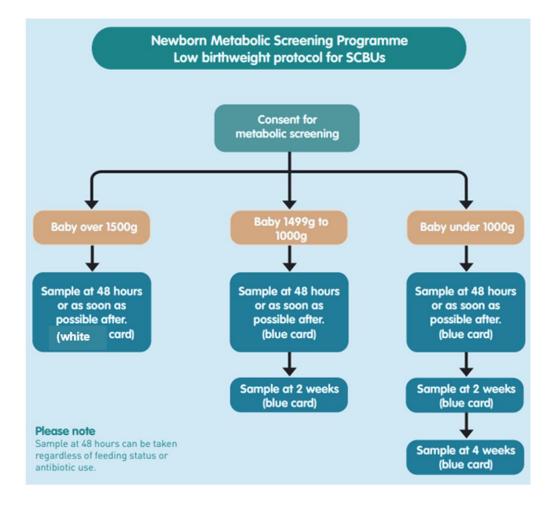
Key Word(s): WCF, WH, Maternity, Newborn, Metabolic, Screening						
EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 4 of 8		

Lakes

5. Low Birth Weight and Sick Babies

Low birth weight and sick babies often receive false positive results due to their immaturity. Different processes have been developed for these babies (see text and diagram below).

- Use a <u>blue coloured blood spot card</u> for babies in SCBU whose birthweight is less than 1500g and a white card for all other babies
- Obtain a sample from all babies at 48 hours of age or as soon as possible thereafter
- For babies with a birthweight <1500g take a second sample at 14 days
- For babies with a birthweight <1000g take a third sample at 28 days



6. Babies Who Have Received Blood Transfusion

- A pre-blood transfusion sample should be taken if possible
- A sample should be taken at 48 hours of age regardless of whether or not an earlier sample was taken
- If a pre-blood transfusion sample was not taken, another sample is required at three months after the last blood transfusion
- The date of the last blood transfusion must be recorded on the blood spot cards

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EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 5 of 8		

Lakes

7. Sending Samples

- Send samples to LabPlus in Auckland as soon as possible once they are dry.
- Avoid grouping or batching samples together before sending as this results in;
 - \circ possible deterioration in the sample and therefore affects testing accuracy
 - o a delay in diagnosis
 - o a delay in treatment if the result is positive

Taupo Maternity:

- Place completed samples in a pre-addressed courier bag on the clip at the staff base
- Courier collects courier bag from Taupo Maternity around 9.00am each week day
- Phone courier to collect any samples on a Friday afternoon or the afternoon of a week day before a public holiday (phone number etc. on a sign at the staff base)

Rotorua Maternity:

• Forms placed in a plastic container at the staff base (Perinatal Ward and SCBU) awaiting collection.

Administrator:

- Collects samples from areas each weekday at 12 noon (again at 4pm on Friday) & Saturday morning.
- Writes sample details in a notebook date, mothers surname, name of LMC or ward area, date sample was taken, courier bag tracking number.
- Books courier pick-up via NZ Post website.
- Places samples in pre-addressed courier bag and sends them via Lamson system to Pathlab Rotorua Hospital aiming for arrival by 12.30pm each day.
- Courier collects courier bag from Pathlab, Rotorua Hospital.

8. Results

- LMC 's and hospital staff are to ensure that they receive all test results within 7-10 days of a child's birth. If not, check that the laboratory has received the sample by using the courier track number or by calling 0800 LABLINK to enquire about the sample and/or result.
- Remember to inform the parents/guardian of the results.
- Record the test result in the baby's clinical notes.

9. When Consent is Not Given for Testing

If, after receiving detailed information about the benefits of NBMS, the parent/guardian declines to have their baby tested;

- \circ Document in the baby's hospital record along with a summary of the information provided
- Complete the relevant details on a NBMS card and write that the parent/guardian declined and, if possible, the reason for this
- \circ Send the card the same as when a sample has been obtained

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EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 6 of 8		

Lakes

10. Request for Return of the NBMS Card

A parent/guardian who does not wish to have the NBMS card stored by the laboratory can have the card returned to them once the screening has been completed.

The parent/guardian needs to complete the 'Return of Newborn Metabolic Screening Samples ('Guthrie Card' Or 'Blood Spot Card') To Family Request Form'. <u>https://www.nsu.govt.nz/system/files/resources/request-form-return-of-card-final.doc</u>

11. Further Staff Education

The 'Best Practice – Newborn Metabolic Blood Spot Collection' e-learning module is available via <u>National Screening Unit website</u> or directly via on <u>Learn Online</u>.

12. Related Documentation

- Well Child Book
- Newborn Record
- Newborn Metabolic Screening Card
- Your Newborn Baby's Blood Test, Information Leaflet, Ministry of Health, Code HE2310. https://www.healthed.govt.nz/resource/your-newborn-babys-blood-test-newborn-metabolicscreening-programme
- Return of Newborn Metabolic Screening Samples ('Guthrie Card' Or 'Blood Spot Card') To Family Request Form. <u>https://www.nsu.govt.nz/system/files/resources/request-form-return-ofcard-final.doc</u>

13. References

- National Screening Unit. (2010). Guidelines for practitioners providing services within the newborn metabolic screening programme in New Zealand. Wellington: Ministry of Health. <u>https://www.nsu.govt.nz/system/files/page/metabolic_screening_guidelines_final_february_20_10.pdf</u> [Accessed April 2022]
- National Screening Unit (NSU), 2018. Newborn Metabolic Screening Programme monitoring indicators.<u>https://www.nsu.govt.nz/system/files/page/newborn-metabolic-screeningprogramme-monitoring-indicators-feb18.pdf</u> [Accessed April 2022]
- National Screening Unit: Newborn Metabolic Screening Programme.
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 [Accessed April 2022].

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EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 7 of 8		

Health New Zealand

14. Audit

Lakes

- Delivery/Transit Time Data:
 - Compiled by the NSU and made available to Te Whatu Ora Lakes should be reviewed each quarter;

See <u>https://minhealthnz.shinyapps.io/nsu-nmsp-transittime/</u> to access Te Whatu Ora Lakes individualised transit time report on whether \ge 95% of samples are received by the laboratory within four calendar days of being taken

- Access NZ Post Tracking website and track courier delivery times for each courier bag sent from Rotorua Maternity using the tracking numbers entered into the NBMS book
- Sampling Time and Quality:
 - Request data from LabPlus on sample date, date sample arrived at the lab, sample or form completion errors etc.

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EDMS: 2531798	Version: 2.2	Issue: Feb 2024	Review: Feb 2026	Page: 8 of 8		