

Newborn Metabolic Screening

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1. Purpose of policy

To ensure that all babies born at Auckland City Hospital (ACH) are offered the Newborn Metabolic screening test from 48 hours of age. This identifies babies with metabolic disorders as early as possible to enable early treatment. It also reduces the chance of illness, disability and even death in babies with metabolic disorders such as hypothyroidism and Phenylketonuria (PKU).

2. Background

The newborn metabolic screening programme is a public health initiative offered to all babies born in New Zealand since 1969. It screens for over 20 rare inborn errors of metabolism, endocrine and other genetic disorders before severe clinical manifestations affect the newborn. In New Zealand, about 50 babies each year are found to have one of the metabolic disorders screened for.

3. Informed consent

Prior to any screening test being performed, informed consent must be gained from the woman/legal guardian of all babies who are born at ACH. No test shall be performed without consent. Consent and decision on storage/return must be documented in each baby's clinical record.

4. Storage/Return and possible uses of blood spot cards

The blood spot card is either returned to the family/whānau if requested or stored indefinitely. Parents/guardians can request the return of their blood spots at any time using the 'Return of newborn metabolic screening samples' form available on the National Screening Unit (NSU) website:

<https://www.nsu.govt.nz/resources/return-newborn-metabolic-screening-samples-guthrie-card-or-blood-spot-card-family-request-form>

The 'Return of newborn metabolic screening samples' form can accompany the sample and no proof of identity is required.

Possible uses of the blood samples include:

- for repeat testing if a baby had one of the disorders but did not have a positive screening result, the sample can be tested again to see why this happened
- To improve the programme, such as by making sure that testing equipment produces accurate results
- To investigate a death or illness in a baby or family/ whānau
- For victim identification, governed by a Memorandum of Understanding with the New Zealand Police
- For research approved by an ethics committee and the Ministry of Health. To date, blood spot cards have not been used for large-scale population studies.

5. Antenatal period

The Lead Maternity Carer (LMC) is encouraged to:

- Discuss with parents/guardians about newborn metabolic screening
- Answer any questions parents/guardians have about the programme
- Document consent / decline to screening
- Document consent / decline to storage/return and possible future uses of blood spot cards
- Ensure that health professionals involved in care whilst baby is admitted at ACH are aware of consent / decline
- Clearly document care plan for the taking of the blood sample (and following up the result)
- Provide follow-up as required in the community by the programme, such as taking repeat samples and reporting results.

Note: A copy of the leaflet entitled ‘Your Newborn Baby’s Blood Test’ should be given to the woman during the discussion.

6. Declining screening

When screening is declined, the midwife must document the decision to decline in both the woman’s and baby’s clinical record and on referral to Well Child/Tamariki Ora and/general practitioner. Decline should be written across the Newborn Metabolic screening card and sent to: **Internal** - Newborn Metabolic Screening, Lab PLUS, Building 31, Grafton Site.

External - Newborn Metabolic Screening, Lab PLUS, Gate 4, Building 31, Auckland City Hospital, Grafton Road, Auckland.

7. Postnatal ward staff

Prior to placing the Newborn Metabolic screening card out for collection by the phlebotomist, the following needs to occur:

- The screening test and storage/return discussion with the woman/ parents has taken place
- Informed consent has been given and documented in the baby clinical records
- If the blood test is to be returned to the parents then the ‘Return of newborn metabolic screening samples’ form accompanies the screening test card.

8. Phlebotomists

Prior to taking blood for the screening test, Phlebotomists are to confirm:

- The screening test and storage/return discussion with the woman/parents has taken place by either the LMC or a midwife staff member and they give consent
- If the woman/ parents indicates the storage/ return discussion has not taken place the phlebotomist is to notify the Charge Midwife and not take the test.
- If the blood test is to be returned to the parents then the screening test card is accompanied by the ‘Return of newborn metabolic screening samples’ form (see [Appendix 1](#))
- All the demographic documentation is correct and completed on the card.

- Verbal consent is obtained from the woman/ legal guardians prior to approaching the baby.
- If the baby is breastfed, encourage the baby to feed at the breast whilst attending the screening Test.

9. Taking the sample

Please refer to the NSU guidelines for detail on taking the blood sample.

<https://www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/how-process-work-1>.

10. Documentation at completion of test

- On completion of the procedure, the person undertaking the screening test records the date, time of the test on the baby's coding front sheet CR0100.

11. Post-natal period

Baby discharged from ACH prior to 48hours of age:

The discharging midwife is responsible to ensure that the postnatal midwife receives handover and is aware that the Newborn Metabolic screen has not occurred. The screening card should be given to the parents.

Baby discharged \geq 48 hours of age:

The midwife is responsible to ensure that the screening test has occurred and is documented in the baby's clinical records, Well Child book and on the electronic discharge summary.

For baby admitted to NICU at 48hours: gaining consent and undertaking the screening is the responsibility of the Newborn Unit team. If the baby is discharged to the ward, this information should form part of the handover process

12. Responsibilities

- The postnatal midwife is responsible to ensure that when the test is completed it is documented in the baby's clinical records, on the maternity electronic system and in the well child book.
- The postnatal LMC is responsible to ensure that the result of the Newborn metabolic test is obtained and recorded in the Well child book (page 49) at the first week Assessment as well as on the 'Transfer of care' referral for a Well-Child Tamariki Ora provider and general practitioner. The results are usually available within 10 days if negative. If the result is positive, the laboratory will phone the LMC or named clinician on the card to arrange retesting.

13. Storage and forwarding of screening tests to National testing centre

- Cards should be dried and sent promptly each day to LabPlus to prevent delays in delivery and testing of samples

- From ACH the cards should be forwarded in the internal mail addressed to:

Newborn Metabolic Screening

LabPlus
Building 31
Grafton Site

- From the community cards should be couriered using the tracked courier bags provided by LabPLUS.

It is advisable to place one of the tracking labels from the bag on the baby's clinical records to enable LabPLUS to track the bag if no result is available due to a missing sample.

14. Reconciliation of all babies born at ACH with National Testing Centre database

A process is in place between ACH and the National testing centre to ensure all eligible babies born at ACH have had a screening test performed or there is a documented decline (see [Appendix 2](#)).

15. Associated documents

- Infection Prevention & Control guideline

Other

- Informed Consent. Available from: <https://www.nsu.govt.nz/about-us-national-screening-unit/informed-consent>
- Your Newborn Baby's Blood Test. Available from: <https://www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/information>
- Return of newborn metabolic screening samples to family request form. Available from: <https://www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test/information>

Information for whānau / family

- Your Newborn Baby's Blood Test

16. Disclaimer

No guideline can cover all variations required for specific circumstances. It is the responsibility of the health care practitioners using this Auckland DHB guideline to adapt it for safe use within their own institution, recognise the need for specialist help, and call for it without delay, when an individual patient falls outside of the boundaries of this guideline.

17. Corrections and amendments

The next scheduled review of this document is as per the document classification table (page 1). However, if the reader notices any errors or believes that the document should be reviewed **before** the scheduled date, they should contact the owner or [Document Control](#) without delay.

Appendix 1: Request for return of newborn metabolic screening sample



Request for return of newborn metabolic screening sample (‘Guthrie card’ or ‘blood spot card’)

How stored newborn metabolic screening samples may be used
After testing, the residual newborn metabolic screening sample is retained in secure storage according to protocols set by the National Screening Unit, Ministry of Health.

If parents have consented, the stored samples may be used in the following ways:

- for repeat testing – if a baby had one of the disorders but did not have a positive screening result, the sample can be tested again to see why this happened
- to improve the programme, such as by making sure that testing equipment produces accurate results
- to investigate a death or illness in a baby or family
- for victim identification, governed by a Memorandum of Understanding with the New Zealand Police
- for research approved by an ethics committee.

For samples taken before June 2011, no research or other tests will be done without the written consent of the person from whom the sample was collected (if over 16 years) or their parent(s)/guardian(s). For samples collected from June 2011, any proposal for research that will require release of samples must first be approved by an ethics committee and then by the National Screening Unit.

INSTRUCTIONS FOR REQUESTING RETURN

Who can request return? Until a child is 16 years old, the request must be made by the baby’s parent or legal guardian. After that time the request must be made by the young person or adult.

If the request for return accompanies the sample and you are the baby’s mother, complete Section A below. No proof of identity is required because this has been established during the sample collection process.

If the blood spot sample has already been sent separately to this request, use the reverse of this form. A photocopy of your driver licence or other photo ID must be supplied. In some cases proof of guardianship is also required.



Completed signed forms must be posted to:
Newborn Metabolic Screening Programme
PO Box 872
Shortland St Mail Centre
Auckland 1140

Or couriered to:
LabPLUS, Gate 4
Building 31, Auckland City Hospital
Grafton Road
Auckland

Emailed or faxed forms will not be accepted. □

The card will be returned by tracked courier with your signature required at the time of delivery. For additional information please contact the Programme Leader, Newborn Metabolic Screening Programme, National Screening Unit: screening@moh.govt.nz Phone: (09) 580 9000

SECTION A: WHERE REQUEST ACCOMPANIES SAMPLE

Please complete this section when the request for the return of the sample accompanies the newborn screening sample and the request is made by baby’s birth mother.

I am the birth mother of the baby named on the attached sample. Please return the sample to me at the address below (must be a street address – courier cannot deliver to a PO Box or Private Bag).

Street address _____

_____ Baby’s NHI _____

Mother’s name: _____ Mother’s signature _____

USE THIS SIDE IF THE BLOOD SPOT SAMPLE HAS BEEN SENT SEPARATELY TO THIS REQUEST

Details of both the requestor and the sample are required. Complete details of sample below then complete either section B, C or D as appropriate. **Please note: addresses for delivery must be your street address, the courier cannot deliver to a PO Box or Private Bag.**

Details of sample (must be completed so the correct card can be identified)

Baby's name _____ Baby's mother's name at time of birth _____

Baby's NHI number (if known) _____ Baby's place of birth _____

Baby's date of birth _____ Lead maternity carer (if known) _____

Additional information such as a hospital number and family doctor or obstetrician (for infants born before 1995) may also be helpful.

Section B: Complete this section when the request for return of the sample does not accompany the newborn screening sample, the child from whom the sample was taken is still under 16yrs and the request is made by the baby's birth mother.

I (name of person requesting return) _____ am the birth mother of the baby described above. I request the return of the newborn screening sample card to me at the address below.

Street address (for return of card) _____

_____ Phone number _____

Mother's signature _____

Proof of identity e.g. photocopy of driver licence or other photo ID must be supplied.

Section C: Complete this section when the request for return of the sample does not accompany the newborn screening sample, the child from whom the sample was taken is still under 16yrs and the request is made by the baby's father or legal guardian.

I (name of person requesting return) _____ am the father/legal guardian of the baby described above, and I request the return of the newborn screening sample card to me at the address below.

Street address (for return of card) _____

_____ Phone number _____

Signature of person requesting return _____

Proof of identity must be supplied e.g. photocopy of driver licence or other photo ID, AND photocopy of birth certificate or other proof of guardianship.

Section D: Complete this section if you are aged 16 years or over and requesting return of your own sample.

I _____ request the return of my newborn screening sample card.

Street address (for return of card) _____

_____ Phone number _____

Signature of person requesting return _____

Proof of identity such as a photocopy of driver licence or other photo ID must be supplied. If you have changed your name since birth, proof of change of name must be provided e.g. a copy of marriage certificate.

Appendix 2: Process for reconciliation of all babies born at ACH with National Testing Centre database

