

NATIONAL TESTING CENTRE (NTC)



RETURN OF NEWBORN METABOLIC SCREENING SAMPLES (GUTHRIE CARDS) TO FAMILY

Use of stored newborn screening samples

After testing, the samples are currently stored for quality assurance purposes. If a baby had one of the disorders and it was not detected by the programme we can review the stored samples to find out why the error occurred and work to ensure the same thing does not happen again.

Stored samples may also be used to set up new screening tests. If this is done all the identifying information about the baby will be removed beforehand so results cannot be traced back to a mother or baby.

No research or other tests will be done on identified samples without the prior written consent of the person from whom the sample was collected (if over 16 years) or their parent(s)/guardian(s).

How is the sample stored?

The screening programme provides secure storage of the samples and information.

When is information disclosed or sample released?

Information is only disclosed in the limited circumstances authorised by the health Information Privacy Code 1994. Samples are only released with the consent of the individual or their parent or legal guardian or under a court order or other legal process.

Who can request return of a baby's test card?

Until baby is 16 years old (or competent to make a decision), the request must be made by the baby's birth mother or other legal guardian. After that time the request must be made by the young person or adult. If the request for return accompanies the sample, no information is required to identify the correct sample and no proof of identity because this has been established during the sample collection process.

Completed **signed** forms must be sent to NTC, P O Box 872, Auckland. Faxed or electronic forms will not be accepted.

For additional information NTC, PO Box 872, Auckland. 09 3074949 x 6570 09 3074936
ntc@adhb.govt.nz

Fill out the bottom of this form (A) if it accompanies the sample and the request is made by the birth mother and the reverse side otherwise.

A Use 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.

Address _____

Mother's name: _____ Mother's signature _____

USE THIS SIDE IF THE SAMPLE HAS BEEN SENT SEPARATELY

1 Details of sample – must be completed so the correct card can be identified. Also section B, C or D.

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

Baby's NHI number _____ Baby's place of birth _____

Baby's date of birth _____ Lead Maternity Carer _____

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

2 Details of requestor – Fill out and sign B, C or D as appropriate.

B Use when the request for return of the sample does not accompany the newborn screening sample and the baby from whom the sample was taken is still under 16yrs, and the request is made by 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.

Address _____

_____ Phone number _____

Mother's signature _____

Proof of identity eg photocopy of passport photo page, drivers licence or other photo ID must be supplied.

C Use when the request for return of the sample does not accompany the newborn screening sample, the baby from whom the sample was taken is still under 16yrs and the request is not made by the birth mother.

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

Address _____

_____ Phone number _____

Signature of person requesting return _____

The person requesting return must supply proof of identity eg photocopy of passport photo page, drivers licence or other photo ID, AND proof of guardianship eg photocopy of birth certificate if father is guardian.

D Use when a person aged 16 years or over is requesting return of their own sample.

I _____ request the return of my 'Guthrie' card newborn screening sample.
Please send the card to the following address

_____ Phone number _____

Signature of person requesting return _____

The person requesting return of the sample must provide proof of identity such as a photocopy of passport photo page, drivers licence or other photo ID. Where the person has changed their name since birth, proof of change of name must be provided such as a copy of Marriage Certificate.