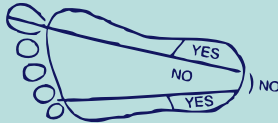


Newborn Metabolic Screening Programme Best Practice Key Messages

Taking the test The quality of the blood sample taken determines the accuracy of the screening test results.
Do not touch the specimen paper (circles).
Fill out all the requested information on the test card prior to taking the blood.



Use automated lancet with a depth of incision less than or equal to 2.4mm.
Wipe off first small drop.

Allow blood to fill spot by natural flow. If blood does not fill the circle another drop may be applied immediately. Collect from one side of the paper only and check blood has soaked through and covered the circle on the other side.

Ensure spot is filled. Repeat for each spot.
Allow spots to dry until they are no longer red (approx 1 ½ hours), then wrap cover over to protect spots.

Timely posting Post cards on the day of testing.
Please do not delay sending by batching samples.
Send to: National Testing Centre,
PO Box 872, Auckland.

Further Information Contact the National Testing Centre: ntc@adhb.govt.nz
Telephone: 09 307 4949 ext 6759
Fax: 09 307 4936

Newborn Metabolic Screening Programme Best Practice Key Messages

- LMC responsibilities**
- Discuss newborn metabolic screening with parent(s) during pregnancy.
 - Provide the information pamphlet "Your Newborn Baby's Blood Test" to parent(s).
 - Discuss newborn screening and obtain consent post-natally before the day of the test. Document the discussion and consent/decline.
 - If consented ensure the heel prick is performed and the blood spot card is sent to the laboratory.
 - Provide any follow-up as requested by the laboratory.

Timing of test Test should be taken at 48 hours or as soon as possible after this, irrespective of feeding status, stool appearance or antibiotic use. Special protocols are available for low birth weight babies. Repeat tests will be requested by the laboratory if required. It is imperative for the baby's wellbeing that the repeat testing is performed as soon as possible.

Preparation for test A poorly perfused heel will not bleed well. Use booties and blankets to warm foot. Breastfeeding and skin to skin contact aid pain relief. Allow foot to hang down to aid blood flow. Sterilise the puncture site and allow to dry.

For more information about the Newborn Metabolic Screening Programme
www.nsu.govt.nz

 National Screening Unit

THE NATIONAL SCREENING UNIT IS A SEPARATE UNIT OF THE MINISTRY OF HEALTH

Newborn Metabolic Screening Programme (NMSP)

The NMSP screens for over 20 metabolic disorders.

Disorder	Cause	Treatment	Incidence/number of babies diagnosed per year in NZ
Congenital hypothyroidism	The thyroid is missing, not functioning or in the wrong place. Can lead to slow growth and developmental delay.	Medication (thyroid hormone)	1 in 4,000 babies approx. 15 babies/year
Cystic Fibrosis	A defective gene and its protein product leads to thick sticky mucus.	Medication Physiotherapy	1 in 7,000 approx. 8 babies/year
Amino Acid disorders (14 disorders) e.g. Phenylketonuria (PKU)	An enzyme is missing. e.g. PKU - without this enzyme an amino acid (called phenylalanine) rises to harmful levels and can lead to brain damage.	Special diet	1 in 12,000 babies approx. 5 babies/year
Fatty acid oxidation disorders (9 disorders) e.g. Medium chain acyl-CoA dehydrogenase deficiency or MCADD	An enzyme is missing. Without these enzymes energy cannot be converted from fats and can lead to coma and death.	Regular feeding (avoidance of fasting)	1 in 12,000 babies approx. 5 babies/year
Congenital Adrenal Hyperplasia (CAH)	An enzyme is missing in the adrenal gland. In severe forms leads to ambiguous genitalia in girls and salt/hormonal imbalances in both sexes.	Steroid medication	1 in 20,000 babies approx. 3 babies/year
Galactosemia	A defective enzyme prevents normal use of milk sugar leading to jaundice, cataracts and life-threatening illness.	Special diet	1 in 100,000 approx. 1 baby every 2 years
Biotinidase deficiency	An enzyme is missing resulting in a deficiency in biotin. This deficiency can lead to seizures, hearing loss and developmental delay.	Vitamin H (biotin)	1 in 150,000 approx. 1 baby every 3 years