RPA Women and Babies Practice Clinical Guideline
Newborn Screening

Background

The NSW Newborn Screening Programme (NBST) now tests for over 30 rare metabolic disorders in every newborn. For many years all infants have been tested for the most common disorders including Phenylketonuria (PKU) 1 in 10,000 live births, Hypothyroidism (primary congenital hypothyroidism) 1 in 3,500 live births, Cystic Fibrosis (1 in 2,500 live births) and Galactosaemia (1 in 40,000 live births). These disorders are readily identified and prevention of adverse outcomes is dependent on early intervention. Using tandem mass spectrometry newborn infants are now also routinely screened for other rare disorders involving fatty acid, amino acid and organic acid defects. Each year the Newborn Screening Programme tests over 90,000 babies and detects about 90 who need urgent assessment and treatment (NSW Newborn Screening Programme 2005).

All clinicians must be cognisant that early diagnosis and immediate treatment of some of the above conditions by medication or diet can prevent death or serious adverse complications including developmental delay (Department of Health, 2005). The midwife must ensure that parents have a copy of the Tests to protect your baby pamphlet on admission to the postnatal ward and RPA Newborn Care (Department of Health, 2005).

Timing of procedure

Following informed consent and documentation of same in the medical notes the test is attended by the midwife / nurse on day 3 or 4 (within 48 – 72hrs of birth) on all infants in the postnatal wards (including those infants on early discharge with MDSP).

Routine newborn screen at one month

Due to concerns regarding inaccurate thyroid assays in some infants, a repeat newborn screen is now performed on all infants with a birth weight less than 1500 grammes at one month of age (Newborn Screening Programme 2005).

The RPA Women and Babies Discharge Liaison Midwife (Micelle Francis) - ext 58415 / page 81025 will receive reminder letters and distribute to RPA Newborn Care, appropriate clinic or Early Childhood Centre. Infants who attend an Early Childhood Centre outside the previous Central Sydney Area Health Service will be asked to return to the hospital or their GP. Please ensure parents of these infants are aware of the need for repeat testing at one month of age.
The NBST can be taken from arterial lines according to RPA Newborn Care hospital protocols (Newborn Screening Programme 2005).

Heel punctures are used to obtain blood samples in newborn infants and should be made on the most medial or lateral portions of the plantar surface of the heel. Punctures should not be done in areas where the calcaneus is present beneath the skin, or on the posterior curvature of the heel (see diagram).

![Puncture sites on sole of infant’s heel (Wong, 2003)](image)

**Procedure**

**Goal:**
To safely collect blood from an infant for the Newborn Screening Test.
To reduce discomfort and pain for the infant during the procedure

**PotentialHazards:**
Invasive procedure
Harmful to baby if blood collected from the incorrect area of the heel
Harmful to staff due to exposure to sharps and blood products
Pain and discomfort for the infant

**Equipment:**
Only automated devices are to be used for heel sampling in RPA Women and Babies (Department of Health, 2005). Under no circumstances are lances to be used for infant blood sampling. Their use has been associated with tissue damage, excessive pain for the newborn and do not comply with current Occupational Health and Safety Guidelines (Shah et al 2003; Department of Health, 2005; McIntosh et al 1997).
Guide for use of automated devices

For infants greater than 3.0kg use the Neonatal Unitstix 2 (incision depth 1.2mm)
OR the Medlance orange top device (incision depth 1.5mm)

For infants 2.0 - 3.0kg use the Medlance yellow top device (incision depth 1.0mm)

Sterile
- cotton balls
- alcowipe
- labelled newborn screening card

Clean
- gloves
- bandaid

Procedure:

Observe all preliminary standards appropriate to this procedure as detailed in this manual

* Explain the NBST to the mother, give information and document in the notes
* It is important that the feeding status is noted on the NBST especially if the infant is on TPN or soy milk as both can alter results (Newborn Screening Programme 2005).
* Obtain verbal consent from the mother for the procedure and document;
* Routine hand wash, put on gloves;
* The procedure should be performed with two care givers, one providing containment and comfort for the infant during the procedure - Encourage mother to breast feed or hold infant during the procedure – multisensory stimulation combined with oral sucrose / breast milk have all been demonstrated to reduce procedural pain in the neonate (Bellieni et al 2001; Carbajal et al 2003; Stevens et al 2003). **Sucrose is a nurse initiated medication and must be signed for on the medication chart.** It cannot be administered by ENs (RPA Newborn Care 2000)
* Position the infant, ensure heel is warm;
* Swab heel with alcohol and wipe dry with cotton ball, select site and prick with automated device - alcohol will haemolyse specimen;
* Using thumb and side of index finger, gently milk blood to the surface;
* **Completely fill the circles on the card with blood, always holding the same side of the card towards the infant's foot - ideally one drop of blood per circle;**
* **Do not touch the circles before / after sampling – this may cause contamination of the specimen and call for re testing** – a situation that can be stressful and inconvenient for parents
* When completed **hold the card horizontal for about 20 seconds**, place a band aid over site – same to be removed by parent / midwife before end of shift;
* Document procedure on the Infant NCP, Blue Book and on the OIS;
* Documentation is to include a signature and date for obtaining parental consent, giving information about the test and completion of the test
* Place the card in a **horizontal position** on the designated rack to dry for at least four hours
* Cards will then be taken sent to transport to be taken to Westmead
Observe all post procedure standards appropriate to this procedure as detailed in the preface of this manual

Outcome:
Blood was collected safely for the Newborn Screening Test
Discomfort to the infant was minimised.

Special considerations
For sick infants in RPA Newborn Care a NBST must be obtained before any blood product (immunoglobulin, platelets or blood transfusion are administered (Bayliss 2005) or an exchange transfusion is first performed (Newborn Screening Guidelines 2005). If this does not occur, a sample must not be taken for at least 48 hours post transfusion and the date / time of transfusion should be noted on the card (Newborn Screening Guidelines 2005). Conditions such as galactosaemia, cystic fibrosis and other metabolic disorders will be invalidated by a blood transfusion (Newborn Screening Programme 2005).

Twin to twin transfusion
In a situation where there has been a twin to twin transfusion, then document this on the Newborn Screening card noting donor / recipient twin (NSW Newborn Screening Programme 2005).

Stillbirth / neonatal death
In the case of a stillbirth the Newborn Screening Card is to be completed and sent to the Newborn Screening Program Children’s Hospital Westmead with a line across the card documenting stillbirth. In the case of impending or actual neonatal death complete a Newborn Screening Card and take blood sample if one has not already been taken and sent. Document “neonatal death” across the card. This will usually only be for babies who die before day 4 (when the NBST is normally taken). Send sample to Newborn Screening Program Children’s Hospital Westmead.
Early Discharge for Mother and Baby not using the MDSP Program

Infants discharged less than 48 hours after birth, and, who are not on the MDSP or transferred to a private midwife or another postnatal healthcare facility, are to have a NBST done prior to discharge. Insert a second NBST card into their Blue Book and instruct the mother to attend an Early Childhood Centre (ECC) when the baby is 4-5 days old. A second sample will be collected. Notify the ECC prior to discharge.

Parental refusal for newborn screening

Parents may refuse the NBST on behalf of their infant however there are about 90 babies/year for which treatment is urgently needed and refusal by parents may place the infant at risk (Department of Health NSW 2005). If parents decline the NBST test for the baby, they need to be seen by the neonatal fellow/consultant and the same documented in the notes.

If parents still decline the test after having been seen by the neonatal team then, offer the option of telephoning the Director/Head of the Newborn Screening Program (9845 3255 / 9845 3659). Fill in the demographic data, i.e. name, date of birth, hospital etc., on the NBST card and the fact that the parents declined the test. The circles will remain blank. This form is then to be sent to Westmead. This is important for medico legal protection of both the hospital and the laboratory (Department of Health NSW 2005). For parents who decline the test, there is a disclaimer for the parent/s to sign confirming that they are declining the test – see appendix one.

If there are problems, the coordinator Newborn Screening will contact the RPA Women and Babies Discharge Liaison Midwife. Her extension number is 58415 / page 81025.

Results/re sampling requests

As a routine, all primary results are available at midday, 24 hours after receipt of sample.

- Results requiring urgent follow-up are telephoned, e-mailed and/or facsimiled to Dr Beeby (public patients/private patients without a paediatric referral) or the specialist paediatrician who is responsible for the baby. Infants in NICU/SCN have the admitting neonatologist/paediatrician documented on their card.

- Only when babies require a further investigation due to abnormal or unsuitable samples is an individual hard copy report sent to the collection source.

- Otherwise, every two weeks a 'Confirmation Report' is sent to each hospital of birth to indicate babies from whom samples have been received. This report also indicates those requiring re-samples. The RPA Newborn Screening Coordinator receives this report.

- If re-samples are not received within two weeks, a repeat request letter is sent to the clinician nominated by the hospital of birth as responsible for the infant.
References:


