



Newborn screening protocol

1. Distribute brochure during 3rd trimester (ideally)

The screening card will look like this:

FREQUENTLY ASKED QUESTIONS?

We have no family history and my baby seems healthy so why should they be screened?

The conditions screened for as part of the newborn screening program do not show any signs or symptoms at birth and usually, there is no family history. By the time symptoms of a condition do show, development may already be impaired. Through screening, affected babies can be identified early and in most cases, treated to prevent or minimise the health impact of the condition.

Is screening safe? What are the risks?

Screening is quick and safe. The heel prick may cause brief discomfort to your newborn, but nothing or feeling from being collected will help. There is a very small risk of infection because we are making a small break in the skin, but using gloves and cleaning the heel beforehand will minimise this risk.

What are the risks of not screening? Are there any alternatives to screening?

Affected babies who are not identified through screening will at some stage develop symptoms and could even die suddenly. While they could be offered treatment when they show symptoms, their growth and development could already be affected. Unfortunately, there are no alternatives to screening – it is the only way to identify sick babies early.

What happens if I choose not to participate in screening?

After discussion with your midwife, if you choose not to participate in screening you will be added to a list of declining screening from and no sample will be collected from your baby. It is recommended, for future reference, that you let your family doctor or maternal and child health nurse know about this decision.

I want my baby screened but I don't want the card used for research. Having the screening card available for research is personal choice and should not deter you from screening. Simply tick 'no' for the research option on the consent form.

Version 3 Printed June 2012

WHAT IS NEWBORN SCREENING?

Newborn screening is a program that identifies babies at risk of having rare, but serious medical conditions that can affect normal development. The screening test is quick and safe and available for all newborns.

Screening is important because:

- affected babies do not show any signs or symptoms of these at birth.
- it allows the conditions to be identified early. With early detection, the conditions can be treated or managed in most cases.
- there are no alternative ways to identify babies with these conditions. By the time symptoms appear, their development may already be impaired.

Fortunately, most of the babies born in Victoria each year are healthy. Only a small number will be found to have one of these serious conditions.

In some cases, the condition may be life threatening if treatment is delayed. In rare cases, the condition may be untreatable.

What conditions are screened for?

The screening test covers around 20 different metabolic conditions. The following table gives information about the most common ones.

WHEN AND HOW IS SCREENING DONE?

Between 48-72 hours after birth, your midwife will collect a few drops of blood onto a screening card by pricking your baby's heel. If you are discharged early, the sample will be collected during a home visit.

WHAT HAPPENS AFTER SCREENING?

Your baby's screening card, which contains the blood sample, will be stored in the laboratory for two years. This happens in case more testing is needed and to make sure the laboratory is meeting quality standards.

After two years, cards are securely stored indefinitely. Access to stored cards is tightly controlled and governed by state legislation. After the two year period of laboratory storage, you can apply to have your baby's screening card transferred to you. Applications must be made in writing to the laboratory and consent from both parents will be required.

Access to stored screening cards

During storage, cards may be accessed:

- for further clinical testing for your baby
- if requested by court order
- by the coroner

Sometimes, the blood from stored screening cards can also be used for ethics approved, de-identified health research. Personal details on the card are not used in such research.

This research may include investigating conditions that affect newborn and young children, such as cerebral palsy, deafness, asthma, infection, metabolic conditions and certain cancers.

On the consent form, you are free to choose whether or not your baby's sample is available for this purpose.

NEWBORN SCREENING FOR THE HEALTH OF YOUR BABY

- ### 2.
- Sample collection needs to occur 48-72hrs after birth
 - Midwives must complete all other patient information
 - Parent/s must fill in and sign the consent section
 - Consent for screening - YES → 3a
 - Consent for screening - NO → 3b

SOAK BLOOD FROM THE OTHER SIDE

VICTORIAN NEWBORN SCREENING LABORATORY

Hospital Name and ward _____

COMPLETE ALL DETAILS OR USE HOSPITAL LABEL BELOW

Baby's FULL NAME _____

Mother's FULL NAME _____

UR _____

Doctor's Name _____

Date of birth / / time 24:00hr

Date of sample / / time 24:00hr

Gestation: weeks Current weight: g Twin ¹/₂

Breast Feed Formula Type TPN Male Female

Relevant Clinical / Family History _____

Collector's Name _____

Newborn Screening Consent

I have received and understood the information in the newborn screening brochure. I consent to my baby having blood collected for the newborn screening test. Yes No

Secondary Research Use

I understand that blood from stored screening cards can be used occasionally for de-identified health research. I choose to make my baby's blood sample available for this purpose. Yes No

Parent Signature: _____

Date Printed 06/2011

3a. screening - YES

Parents free to choose YES or NO for research use.

Collect blood sample, dry and send to laboratory.



SOAK BLOOD FROM THE OTHER SIDE

VICTORIAN NEWBORN SCREENING LABORATORY

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Baby's FULL NAME _____

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Newborn Screening Consent

I have received and understood the information in the newborn screening brochure. I consent to my baby having blood collected for the newborn screening test. Yes No

Secondary Research Use

I understand that blood from stored screening cards can be used occasionally for de-identified health research. I choose to make my baby's blood sample available for this purpose. Yes No

Parent Signature: Jane/John Smith

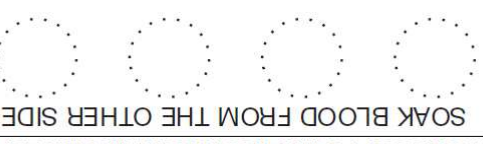
Date Printed 06/2011

3b. screening - NO

Discuss reasons with parents, refer/offer counselling.

Fill in screening card, have parents sign & send to lab as normal (lab record of refusal)

Complete a hospital decline form and place in mum's medical file (hospital record of decline).



SOAK BLOOD FROM THE OTHER SIDE

VICTORIAN NEWBORN SCREENING LABORATORY

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COMPLETE ALL DETAILS OR USE HOSPITAL LABEL BELOW

Baby's FULL NAME _____

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Newborn Screening Consent

I have received and understood the information in the newborn screening brochure. I consent to my baby having blood collected for the newborn screening test. Yes No

Secondary Research Use

I understand that blood from stored screening cards can be used occasionally for de-identified health research. I choose to make my baby's blood sample available for this purpose. Yes No

Parent Signature: Jane/John Smith

Date Printed 06/2011

+ hospital decline form



suggested wording for decline forms

- I understand the information in the newborn screening brochure.
- I do **not** consent to blood being collected from my baby for the newborn screening test.
- I understand that choosing **not** to have my baby screened could lead to a delay in diagnosis and treatment of a serious medical condition.
- I understand that a delay in treatment could affect normal development and in rare cases may cause death, should my baby have a condition detectable by newborn screening.
- I have discussed my decision with a midwife or health professional.

Parent Signature _____

Parent Name _____

Midwife/Health Professional _____

Date _____

Newborn Screening Laboratory
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