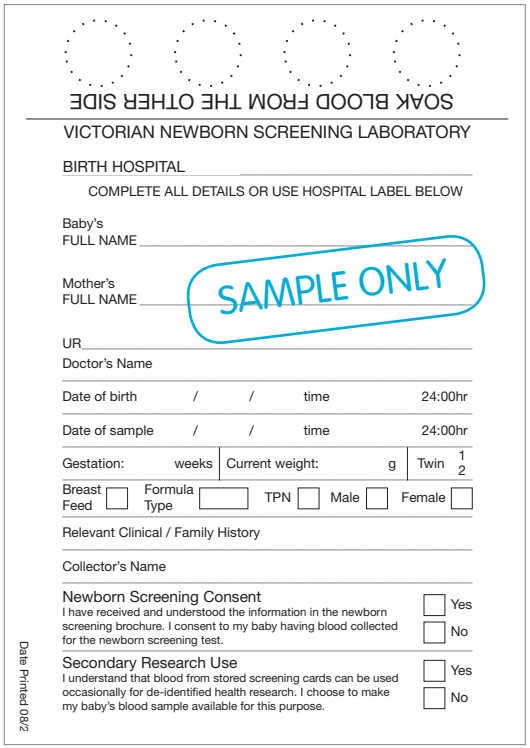
**The bloodspot screening card looks like this.**



SOAK BLOOD FROM THE OTHER SIDE

VICTORIAN NEWBORN SCREENING LABORATORY

BIRTH HOSPITAL

COMPLETE ALL DETAILS OR USE HOSPITAL LABEL BELOW

Baby's FULL NAME

Mother's FULL NAME

SAMPLE ONLY

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

Date Printed 08/2

## More information

If you are unsure about newborn bloodspot screening or have any questions, you can:

- speak to your midwife;
- view detailed information at vcgs.org.au/tests/newborn-bloodspot-screening or;
- arrange to speak to a newborn bloodspot screening counsellor at the Victorian Clinical Genetics Services.

## Contact us

Victorian Clinical Genetics Service
Flemington Road, Parkville VIC 3052
P 1300 118 247
W vcgs.org.au

## 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 bloodspot screening program, usually do not show any signs or symptoms at birth and often 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 bloodspot screening safe? What are the risks?**

Screening is quick and safe. The heel prick may cause brief discomfort to your newborn, but holding or feeding them during collection 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 bloodspot 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 bloodspot 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 asked to sign a 'decline of screening' form 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 a personal choice and should not deter you from screening. Simply tick 'no' for the research option on the consent form.

VICTORIA State Government

VCGS Leaders in Genetic Health

BG-W-254 v2 25/7/2019

VCGS Leaders in Genetic Health

# Newborn Bloodspot Screening

For the health of your baby

## What is newborn bloodspot screening?

Newborn bloodspot 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 may not show any signs or symptoms of illness 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 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 does bloodspot screening detect?

The screening test covers around 25 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.

Before a sample is collected, you must give your consent and sign the screening card. If you choose not to have your baby screened, you will also be asked to sign a separate 'decline of screening' form.

Samples for bloodspot screening are sent to the screening laboratory based at The Royal Children's Hospital in Melbourne. In over 99 per cent of cases, the results are normal. When this happens, parents are not contacted; final results for a small number of babies may take up to 6 weeks.

If your baby has an abnormal screening result, you will be contacted and referred to a specialist for further testing.

Sometimes, a repeat blood sample may be needed by the laboratory. This can happen for a number of reasons. Your midwife will arrange for a re-collection. Most repeat results are normal.

| Disorder | Caused by | Problems if untreated | Treatment/ management |
|---|---|---|---|
| congenital hypothyroidism | thyroid gland unable to produce thyroid hormone (T3 & T4) | growth failure, intellectual impairment | thyroid hormone supplements |
| cystic fibrosis | abnormal secretions in the body; in particular the lungs & pancreas | impaired digestive & respiratory function, infections & decreased life span | dietary supplements, physiotherapy |
| amino acid disorders* (e.g. phenylketonuria PKU) | defective enzymes that break down protein | developmental delay, intellectual impairment, seizures | dietary modifications, vitamin supplements |
| fatty acid oxidation disorders* | defective enzymes that turn fat into energy | muscle problems, poor feeding, vomiting, seizures, sudden death | avoid prolonged fasting, dietary modifications |

* These disorders affect the breakdown of fat & protein in the body

## 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 protected 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.