# Frequently asked questions cont.

#### What if my baby and I are discharged prior to 48 hours?

If you and your baby are discharged prior to 48 hours your midwife will discuss your options to get the test completed.

#### Why does it have to be done between 48-72 hours?

Between 48 and 72 hours is when the test is most accurate. If you cannot get the test done between 48 and 72hours it is still recommended you have the test done.

## What happens next?

Once received, samples are normally processed within 24 hours and stored securely by QLD Health. Access is restricted and the test can only be used to screen for the diseases you have consented too. If a positive result is identified your doctor or nurse will contact you.

#### Does my baby have to have the test?

We recommend all babies have the test, but it is voluntary and requires your consent prior to our staff performing the test. You can choose not to have your baby tested.

### What happens if I choose not to have my baby tested?

If you choose not to have your baby tested, you will be asked to sign the card to show you understand the risks of not having the test. You need to let your GP and child health nurse know about your decision, especially if your baby gets sick.

If you are worried about your baby having the NBS, or have any questions, please contact your care team, or scan the QR code below to view the NBS parent/carer video.

## Caboolture Hospital

Maternity Ward Ph: 5433 8629

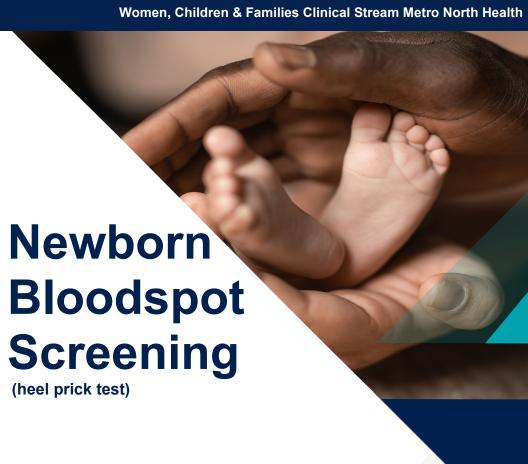
## Redcliffe Hospital

Maternity Ward Ph: 3883 7709

## The Royal Brisbane & Women's Hospital

Maternity Ward Ph: 3646 7455





Tests to protect your baby's future health and wellbeing



# What is Newborn Bloodspot Screening (NBS)?

Newborn bloodspot screening identifies babies at risk of having rare, serious medical conditions that can affect their development and it is strongly recommended for all babies.

NBS is important because:

- Affected babies may not show any signs of being sick and there may be no family history
- If a rare condition is identified, early treatment and management can be started, improving outcomes for your baby
- There is no other way to identify babies with these conditions. By the time your baby appears sick, their development may already be impaired. In some cases, the condition may be life threatening if treatment is delayed.

## When and how is NBS done?

The test should be taken when your baby is 48 to 72 hours old. It is a quick and safe heel prick that takes only a few small drops of your baby's blood onto a screening card. It can cause some discomfort for your baby, so we recommend feeding and/or swaddling your baby during the test, to make them feel as comfortable as possible.

Your doctor or midwife will discuss the advantages of having the test done and seek your consent prior to performing the test. If you choose not to have it done, you will still be asked to sign the card to show you understand the risks of not having the test.

If you are discharged before 48hours, your midwife will tell you how to get your NBS done.



## What does NBS test for?

The test looks for more than 25 different conditions. The table gives you some information about the most common conditions:

Disorder	Caused by	Problems if untreated	Treatment/ Management
Phenylketonuria (PKU)	Defective enzymes that break down protein	Developmental delay, intellectual impairment, seizures	Dietary modifications, vitamin supplements
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 lungs & pancreas	Impaired digestive & respiratory function, infections & decreased life span	Dietary supplements, physiotherapy
Galactosaemia	Build up of galactose	Liver failure, intellectual disability, seizures	Special milk diet
Congenital Adrenal Hyperplasia (CAH)	Defects in enzymes necessary for cortisol production	Early puberty, infertility & failure to thrive	Lifelong steroid therapy

# What happens after screening?

You will be contacted by your doctor ONLY if the screen result shows an abnormality. An abnormal result does not always mean your baby has a condition. It means that your baby has an increased risk of having the condition and further testing is required. If you have not heard from your doctor after one month your baby's test was normal.

## Frequently asked questions

How often are these conditions detected? About 1 in 800 babies born in Queensland will have one of these conditions.

# We have no family history, so why should my baby be tested?

Babies with these rare conditions may not show any signs or symptoms of illness at birth and often there is no family history. This test is the only way to identify these rare conditions.

