

How good is newborn bloodspot screening at finding babies at high risk of having one of these conditions?

Newborn bloodspot screening does not make a diagnosis. It shows only that a baby is '**at high risk**' of having one or more of the conditions screened for.

Sometimes screening results can suggest a baby is at high risk of having one of the conditions, but when more tests are done the baby actually does not have the condition. This is called a '**false positive**'. False positives can be very worrying for parents and families, but they are very rare.

Sometimes the screening result does not identify a possible health risk. This is called a '**false negative**'. A false negative means that the screening result does not show that a baby is at high risk, but the baby may actually have one of these conditions. False negatives are extremely rare. But if you have any concerns about your baby, discuss them with your family doctor (GP) or public health nurse.

I would like to have my baby screened. What should I do?

Your midwife or public health nurse will talk to you about screening and give you information. Please read the information carefully. If you have questions, please ask your midwife or public health nurse.

If you want to have your baby screened, sign the newborn bloodspot screening card you are given. Signing this card is how you confirm that the information about your baby is correct and how you agree (consent) to the screening.

What if I feel unsure about this screening?

If you are unsure about screening, please talk with your midwife or public health nurse. They will be able to discuss your concerns and explain more about the screening.

If you are still unsure, your midwife or public health nurse will offer you the opportunity to speak with a senior officer in the National Newborn Bloodspot Screening Laboratory in the Children's University Hospital, Temple Street.

If you decide not to get your baby screened, you will be asked to sign a form that says you understand the risks of not having your baby screened. If you change your mind, please talk to your public health nurse or family doctor (GP). They can arrange to have your baby screened.

Where can I get more information?

For more information on newborn bloodspot screening:

- visit the website www.newbornscreening.ie
- talk to your midwife or public health nurse

Plain English
Approved by NALA



What you need to know about newborn bloodspot screening - "heel prick"

Information for Parents and Guardians



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In the first week after your baby is born, you will be offered newborn bloodspot screening for your baby. This is often called the 'heel prick'.

Newborn bloodspot screening is an essential part of newborn care. It helps identify babies who may be at high risk of having a rare but serious condition. Most babies who are screened will not have any of these conditions. But for the small number of babies who do, the benefits of screening are enormous.

What conditions are included in newborn bloodspot screening?

In Ireland, all babies are now screened for:

- Cystic fibrosis
- Congenital hypothyroidism
- Phenylketonuria
- Maple syrup urine disease
- Homocystinuria
- Classical galactosaemia
- Glutaric aciduria type 1
- Medium chain acyl CoA dehydrogenase deficiency

You can read more about these rare conditions on www.newbornscreening.ie. You can also discuss these with your midwife or public health nurse.

Why would my baby have one of these conditions?

Most of these conditions are inherited. This means the baby gets the genes that cause the condition from their parents. This also means there is a risk that other babies born to these parents may have the same condition.

Why should I have my baby screened?

Each year, newborn bloodspot screening identifies about 110 babies with one of these rare but serious conditions. The health of these babies can then be managed before they develop severe symptoms. Unmanaged, these conditions can cause a serious risk to health or life.

Some parents worry that their baby will be uncomfortable during the heel prick. But the long-term benefit of screening is much greater than the small discomfort a baby feels when the blood sample is taken.

When is the screening done?

Newborn bloodspot screening is usually done between three and five days after your baby is born.

How is the screening done?

The midwife or public health nurse will prick your baby's heel with a sterile needle to collect drops of blood onto a special card. They will then hold your baby's ankle to ensure the blood goes onto the card. This may take a couple of minutes. Your baby may feel uncomfortable and may cry. You can help by making sure your baby is warm and comfortable by cuddling and feeding them.

What happens after the heel prick is done?

When the sample is collected, the card is sent to the National Newborn Bloodspot Screening Laboratory at the Children's University Hospital, Temple Street, Dublin.

What happens to my baby's screening card after screening?

After screening, the results and the card are stored securely by Children's University Hospital, Temple Street, as part of your baby's health record. The card will be stored securely for at

least 10 years after which it will be disposed of as per current policy. The stored cards may be used for:

- checking your baby's results or for other tests that your doctor recommends, but only after you give your permission, and
- improving the screening programme and the health of babies and their families in Ireland.

Newborn bloodspot screening cards are sometimes used in research but never for commercial gain. When cards are used, babies are never identifiable.

Will my baby need to be screened more than once?

Sometimes a screening result is not clear or not enough blood was collected. If this happens, your midwife or public health nurse may need to contact you and ask to take a second blood sample from your baby's heel.

How will I hear about the results?

If the screening shows that your baby is not at high risk of having any of the conditions, you will not be contacted. If you would like a copy of the screening results, you can ask your public health nurse for them at your next visit.

If the screening shows your baby is at high risk of having one of these conditions, a nurse or doctor will contact you as soon as possible.

What happens if the screening says my baby is at risk?

If the screening shows your baby is at high risk, they will need to have more tests to confirm whether or not they do have the condition. They may need to stay in hospital for a short time while this is done.