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

Information for parents and guardians

mychild.ie

Important test for newborns can save lives

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

Newborn bloodspot screening is an essential part of newborn care. It helps to identify babies who may be at increased risk of having any of 11 rare but serious conditions (see page 4).

If these conditions are not diagnosed and treated early, they can cause serious health issues. Some can even be life-threatening.

Most babies will not have any of these conditions. But for the small number who do (around 130 babies a year) the benefits of screening are very significant.

We can then offer these babies treatment at an early stage. This can dramatically improve their long-term health and development.

Why would my baby have one of these conditions?

Most of these conditions are inherited. This means genes that cause these conditions are passed on from parent to child. It also means there is a risk that other babies born to these parents may have the same condition.

When is the screening done?

Newborn bloodspot screening is usually done between 3 and 5 days after your baby is born. The blood sample will be taken in the hospital or at home when the public health nurse first visits you and your baby.

How is the screening done?

The midwife or public health nurse will prick your baby's heel to collect drops of blood onto a screening card. They will hold your baby's foot while the blood drops onto the card. This may take a couple of minutes.

What giving your consent means?

It is your choice to take part in screening or not.

To consent to newborn bloodspot screening, you must be the legal guardian (birth mother or married father).

You will be asked to give consent on behalf of your baby.

You do this by signing the newborn bloodspot screening card before the blood sample is taken from the baby.

If you cannot sign the screening card, you will be asked to give your consent either verbally or by making a mark on the screening card in front of the midwife or public health nurse.

By signing the screening card, you confirm the following:

- You are the baby's legal guardian.
- You got and understood information from the HSE about heel prick screening.
- The information that is written on the screening card about your baby is correct.
- You consent to having your baby screened. This involves different laboratory tests. Screening will include a genetic test for spinal muscular atrophy only. It may include a genetic test to screen for cystic fibrosis.
- You consent to how we use and store your personal information (see pages 7 and 8).
- You consent to the screening card being stored for 10 years.
- You consent to other uses of the screening card and personal information as described in this parent information leaflet.

How can I prepare for screening?

It is natural to worry about your baby feeling uncomfortable during the heel prick test. The test causes only a moment of discomfort but helps detect these rare and serious conditions early. This means, if needed, we can give your baby the right treatment quickly.

If possible, put two pairs of socks on your baby for an hour or so before the test. This will make sure the baby's heel is nice and warm. This helps the blood flow more easily and makes it more comfortable for your baby.

You can also help to reduce any discomfort your baby may feel during the heel prick test by cuddling them, or feeding the baby at the time of the test.

What happens after the heel prick is done?

After the midwife or nurse collects your baby's sample, they will send it to the National Newborn Bloodspot Screening Laboratory. Laboratory staff will check the sample for any sign that your baby might be at increased risk of having one of the 11 rare conditions.

What conditions are included in screening?

Babies are screened for 11 rare conditions. The conditions are:

- adenosine deaminase deficiency severe combined immunodeficiency
- classical galactosaemia
- congenital hypothyroidism
- cystic fibrosis
- glutaric aciduria type 1
- homocystinuria
- maple syrup urine disease
- medium chain acyl-CoA dehydrogenase deficiency
- phenylketonuria
- severe combined immunodeficiency
- spinal muscular atrophy.

You can read more about these conditions on:
www2.hse.ie/conditions/heel-prick-screening/

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

After screening, the National Newborn Bloodspot Screening Laboratory will store the results and the screening card securely as part of your baby's health record. They will store the card for 10 years. After this time the card will be disposed of.

The stored cards may be used:

- to check your baby's screening result
- for other tests that your doctor recommends for your baby (you will be asked for your consent).

Expanding the screening programme

In the future, we may add new conditions to the screening programme.

If a new condition is added, the laboratory will need to test bloodspot samples. This is to make sure that the new screening test works well. These tests may include genetic tests specific for the condition that the screening programme has been requested to add.

All samples used for this reason are anonymised. This means names are removed. The sample cannot be traced back to an individual child.

Samples are never used for commercial purposes.

Will my baby need to be screened more than once?

Sometimes a screening result is unclear or not enough blood was collected. If this happens, your midwife or public health nurse will 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 at increased risk of having one of these conditions, a nurse or doctor will contact you as soon as possible.

If the screening shows that your baby is not at increased risk of having any of the conditions, we will not contact you.

However, if you would like a copy of the screening results, you can ask your public health nurse for them.

How good is newborn bloodspot screening at finding babies with these conditions?

Newborn bloodspot screening does not make a diagnosis. It shows only that a baby is **'at increased risk**' of having one of the conditions screened for. In this situation, your baby would need to have more tests to confirm if they have the condition or not.

Screening will not detect all cases of all conditions screened for.

Sometimes, screening results can suggest that a baby is at increased risk of having one of the conditions, but when more tests are done the baby does not have the condition. This is called a **'false positive'**. False positives can be very worrying for parents and families, but they are rare. A doctor or nurse will support you through this.

Sometimes, screening results can suggest that a baby is not at increased risk of having one of the conditions, but the baby is later found to have that condition. This is called a **'false negative'**. False negatives are very rare. But if you have any concerns about your baby's health, discuss them with your family doctor (GP) or public health nurse.

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

If the screening shows your baby is at increased risk of having one of the conditions screened for, your baby will need to have more tests to confirm if they have the condition or not.

The baby may need to stay in hospital for a short time while this is done.

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

Screening is available to all babies in Ireland under 1 year of age. Your midwife or public health nurse will talk to you about screening.

If you want to have your baby screened, you will be given the newborn bloodspot screening card to sign.

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 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 then arrange to have your baby screened.

How do we use personal information?

The National Newborn Bloodspot Screening Programme collects and securely stores all the information provided on the newborn bloodspot screening card. For example, name, address, phone number and date of birth.

We also securely store your baby's newborn bloodspot screening results.

The information on your baby's screening card and their screening results are securely stored by the healthcare professionals who deliver the screening programme.

These healthcare professionals may use this information to contact you. For example, if your baby needs a repeat bloodspot screening card or a further screening test.

Information from the Irish bloodspot screening programme may also be used for:

- national and international quality assurance
- evaluation of the screening programme.

Information used for this purpose is anonymised.

We will never use your name or your baby's name in any reports or in any programme reviews.

We will keep you and your baby's personal information safe, secure and confidential in line with current data protection regulations.

Communicating with you

We will communicate with you in an open, honest, timely and transparent manner if something goes wrong with regard to the screening programme and your baby.

Where can I get more information?

For more information on newborn bloodspot screening:

- visit the website www2.hse.ie/conditions/heel-prick-screening/ - translated information is available (see QR code below right)
- talk to your midwife or public health nurse.

Data privacy

For more information on data privacy, visit www.hse.ie

Data access

To find out how to request access to your baby's records, visit www.hse.ie

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