NEWBORN BLOODSPOT SCREENING TEST

INFORMATION FOR PARENTS AND GUARDIANS

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

In the first week after your baby is born, you will be offered a Newborn Bloodspot Screening Test for your baby. It is often referred to as the 'heel prick' test. This test helps identify babies who may have a rare but serious condition.

WHAT CONDITIONS ARE INCLUDED IN THE NEWBORN BLOODSPOT SCREENING TEST?

In Ireland, all babies are now screened for:

- phenylketonuria
- maple syrup urine disease
- homocystinuria
- galactosaemia
- cystic fibrosis (begins during 2011)
- congenital hypothyroidism

You can read more about these conditions on www.newbornscreening.ie, or ask your midwife or public health nurse. Other conditions will be added in the future.

WHY SHOULD I HAVE MY BABY SCREENED?

Most babies who are screened will not have any of these conditions. For the small numbers of babies who do, the benefits of screening are enormous. Screening means that babies who have a condition are treated early. Early treatment can improve their health and prevent severe disability or even premature death.

WHY WOULD MY BABY HAVE ONE OF THESE CONDITIONS?

Most of these conditions are inherited. An inherited condition means the baby received 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.

SCREENING IS IMPORTANT

Screening your baby for all these conditions is strongly recommended. If your baby has any of the conditions, the long-term benefit of screening is much greater than the small discomfort they feel when the blood sample is taken. However, you can choose not to have your baby screened.

HOW DO I AGREE TO SCREENING FOR MY BABY?

Before your baby has the heel prick test you should read this leaflet carefully. You will be asked to sign the newborn bloodspot screening card to confirm that you agree to the test and that the information about your baby is correct. If you do not want your baby screened you should speak with your midwife or public health nurse. You will be asked to sign a form that says that you understand the risks of not having your baby tested.

HOW IS THE TEST DONE?

The Newborn Bloodspot Screening Test is usually done between 72 hours (three days) and 120 hours (five days) after your baby is born. The midwife or public health nurse will prick your baby's heel to collect some drops of blood onto a special card.

You can help by:

- making sure your baby is warm and comfortable, and
- being ready to feed or cuddle your baby

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.

Some babies have a risk of having a condition called galactosaemia, which means they cannot break down a sugar found in human and cow's milk. The risk is higher if someone in your family already has the condition, or for babies of Traveller parents. Babies with a higher risk will be tested at birth, and parents will be asked to use soya-based formula milk until the results are known.

ARE REPEAT BLOOD SAMPLES EVER NEEDED?

Occasionally the midwife or public health nurse will contact you and ask to take a second blood sample from your baby's heel. This may be because the test result was not clear or not enough blood was collected. The repeat results are usually normal.

HOW WILL I HEAR ABOUT THE RESULTS?

Most babies will be found not to have any of the conditions. If the test results show that your baby does not have any of the conditions, you will not be contacted. You can ask your public health nurse for the results of the test at your next visit.

If the test results show your baby may have one of the conditions, a nurse or doctor will contact you within one to two weeks of the test. Your baby will need to have more tests to confirm the result and may need to stay in hospital for a short time. Not all babies with these conditions will be detected by newborn screening.

WHAT HAPPENS IF MY BABY HAS ONE OF THESE CONDITIONS?

If your baby has one of these rare conditions, a team of specialist health professionals will work with you to manage your baby's condition. Most babies with these conditions will grow healthy and well, once they start getting treatment.

WHAT HAPPENS TO MY BABY'S SCREENING CARD AFTER SCREENING?

After screening a bloodspot card may be used for:

- checking your baby's results or for other tests recommended by your doctor, for which your permission will be sought.
- quality assurance to develop and improve the screening programme and the health of babies and their families in Ireland.

The bloodspot card is stored as part of your baby's health record for 10 years by the National Newborn Bloodspot Screening Laboratory on behalf of the HSE. After this time the Bloodspot Cards are shredded and securely disposed of. The test results are recorded and retained in compliance with the HSE Code of Practice for Healthcare Records Management: Retention and Disposal Schedule.

WHERE CAN I GET MORE INFORMATION?

You can get more information on Newborn Bloodspot Screening from your midwife or public health nurse, or on **www.newbornscreening.ie**

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