multicultural health communication

Produced by NSW GOVERNMENT Health

English
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Newborn Screening: Tests to protect your baby

The following article is produced by NSW Department of Health.

Please keep this information until your baby is 3 months old in case you need to refer to it again.

Early detection of rare disorders
Newborn babies are given this important test before they go home from hospital, between 48 to 72 hours from birth. It is part of the routine care for your baby.

Over 30 rare disorders can now be detected by the newborn screening test. Staff will discuss the test with you, and why it is important for your baby's health. Staff must obtain your verbal consent first in order to do the test.

About 90 babies with rare medical disorders are detected each year by newborn screening.

If it is found that your baby is affected by a disorder of this kind, treatment can be started early, before your baby becomes sick.

For the test, a few drops of blood are taken from your baby's heel on to special absorbent paper. The dried blood sample is sent to the NSW Newborn Screening Laboratory, located at The Children's Hospital at Westmead.

PLEASE MAKE SURE YOUR BABY HAS THIS TEST AND THE DATE OF TEST IS WRITTEN IN YOUR BABY'S PERSONAL HEALTH RECORD

Information about the disorders
Congenital Hypothyroidism:
This occurs in about 26 babies each year in NSW/ACT. It is caused when the thyroid gland is too small, is absent or doesn't work properly. Early treatment leads to the normal mental and physical development of your child. Treatment is a small tablet of thyroid hormone given daily.

Phenylketonuria:
This occurs in about 10 babies each year in NSW/ACT. A baby with this problem cannot properly use phenylalanine (which helps build protein in the body).If untreated, phenylalanine accumulates in the blood and causes brain damage. Treatment is a low phenylalanine (protein) diet and your baby will develop normally.

Galactosaemia:
This occurs in about 1-3 babies each year in NSW/ACT. It is caused by one of the sugars (galactose) contained in milk (both breast and cows' milk) accumulating in the blood. Serious illness will be prevented if the child is treated promptly with special milk, which does not contain galactose. Babies with this condition who are not treated may become very sick and die.

Cystic Fibrosis:
This occurs in about 34 babies each year in NSW/ACT. It is caused by the body producing thicker mucus than normal in the bowel and the lungs. This can cause chest infections or diarrhoea and could stop the baby gaining weight. Recent medical and scientific advances have greatly improved the outlook for these babies.

Other disorders
New technology has made it possible to detect a number of extremely rare disorders, using the dried blood sample, so that treatment can be started early. These much rarer medical disorders together affect about 15 babies each year, and include fatty acid, organic acid and amino acid defects. The commonest of these disorders is MCAD (medium-chain acyl CoA dehydrogenase deficiency). Early detection is important as diet and medications can treat most of these disorders. Without appropriate management they can cause severe disability or death.

Early diagnosis and treatment are important for all the disorders discussed above.

Test Result
Parents are not notified of a normal test result.

About one baby in every 100 will need a second blood test if the first test did not give a clear result. Parents will be notified if a second test is needed. The second test will almost always give a normal result, and your doctor will be sent the result.

In a small number of babies the blood test will be abnormal, further investigations will be necessary, and treatment may be needed. Your doctor will be told about the result and will contact you.

After the dried blood has been tested, it will be stored in the laboratory. Rarely, it may be used at a later time to provide new medical information for the benefit of the family. The stored samples may be used for research after all identification has been removed. However, no further tests on your baby's identified sample will be performed without written consent from both parents or the guardian.

Information current as at May 2003

NSW Newborn Screening Programme, The Children's Hospital at Westmead.
http://www.chw.edu.au/prof/services/newborn

If you need help making phone calls in English, ring the Translating and Interpreting Service (TIS) on 131 450.

You can find more health information in your language on the Multicultural Communication website at http://www.mhcs.health.nsw.gov.au

Telephone numbers are correct at time of publication but are not continually updated. You may need to check the numbers in the telephone directory.

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