



pennsylvania
DEPARTMENT OF HEALTH

IMPORTANT INFORMATION
For Parents About
**NEWBORN
SCREENING**



NEWBORN SCREENING...

A special time...

A special test...

This brochure describes the newborn screening tests your baby will receive. There are three parts to newborn screening: heel sticks to collect a small blood sample, a pulse oximetry to measure the amount of oxygen in the baby's blood, and a hearing screening. These tests should be performed when your baby is 24 to 48 hours old. If you had your baby in a hospital, the newborn screening tests will be completed prior to being discharged. If you gave birth at home or in a birthing facility, the midwife or doctor attending your birth will provide information as to what steps need to be taken to have the newborn screening tests completed for your baby. Newborn screening does not confirm a baby has a condition. If the result of one of these tests is "abnormal," your baby's doctor and you will be contacted immediately and additional testing will be needed. This brochure provides information about where you can go for help after an abnormal test.

By Pennsylvania law, your baby's blood filter paper test cannot be used for scientific research by any laboratory without your signed permission.

BLOOD SPOT TESTING

It is important that you talk to your baby's doctor before birth to determine which conditions your baby will be screened for at your birthing facility. Different birthing facilities screen for different conditions, so don't assume that your baby will be screened for all conditions on the list. If you would like your baby screened for a condition that is on the list but your birthing facility indicates it is not a standard condition that they screen for, you can request that your baby be screened for that condition.

Blood spot testing is a test done on ALL babies born in Pennsylvania for conditions that can cause serious illness, mental retardation or death if left untreated. Shortly after birth, your baby will have screening tests to detect a variety of metabolic and genetic conditions. A few drops of blood are taken from the newborn's heel, placed on a filter paper and sent to the newborn screening laboratory for testing. Test results are usually known within seven to 10 days. After testing is completed, the results of the tests are sent to the submitter and the baby's doctor to become a permanent part of the baby's medical record. Although these conditions are considered rare, early diagnosis and proper treatment can make

the difference between lifelong impairment and healthier outcomes. For a complete list of all newborn screening blood spot tests, please go to: www.doh.pa.gov/newbornscreening

HEARING SCREENING

Hearing screening is a test to tell if a newborn might have hearing loss. Hearing screening is not painful for your baby. There are two ways to screen your baby's hearing. The first test measures a tiny sound to determine if your baby is hearing properly. This test is called an Otoacoustic Emissions (OAE) test. The second test measures the baby's nerve response to sound. This is called an Auditory Brainstem Response (ABR). All babies should be screened for hearing loss no later than 1 month of age. It is best if they are screened before leaving the hospital.

If a newborn's hearing loss is not found and treated, the child may:

- be slow in learning to speak or use sign language;
- have problems learning at school; and
- suffer from social and emotional problems.

A small number of babies who pass the screening at birth can lose their ability to hear – suddenly or gradually

– before they are 1 year of age or older. Repeated ear infections, meningitis, head injury or other medical conditions are some of the causes of hearing loss in children. Children with a history of these conditions should receive hearing tests more frequently.

If you have any questions about hearing screening, ask your baby's doctor. If your baby is diagnosed as deaf or hard of hearing, Early Intervention services, located in every county in Pennsylvania and provided at no cost can:

- help find answers to your questions about hearing loss;
- teach you how to communicate and care for your baby; and
- help you acquire hearing aids and other listening devices.

For more information on the Pennsylvania Newborn Hearing Screening Program, go to:

www.doh.pa.gov/newbornscreening

CRITICAL CONGENITAL HEART DEFECT (CCHD)

Babies born with congenital heart defects are at significant risk for death or disability if their condition is not diagnosed soon after birth. Pulse oximetry screening measures the amount of oxygen in the blood and pulse rate. Pulse oximetry screening

can detect a possible heart defect. All babies should be screened using pulse oximetry between 24–48 hours after birth. Babies with a CCHD should be seen by cardiologists and can receive specialized care and treatment that could prevent death or disability early in life.

How does the Department of Health's Newborn Screening and Follow-Up Program help you?

The Newborn Screening and Follow-Up Program's role is to help notify your baby's doctor if your baby has an "abnormal" result for any of the conditions screened for at birth, and if appropriate follow-up services or further testing for confirmatory diagnosis are needed.

May I say NO to the tests?

Yes, you may ask not to have the tests done for religious reasons. If you say "no," this will be recorded in your baby's record with your signature. However, if your child is born with one of these conditions, your child will not have the benefits of early treatment.

FOR MORE INFORMATION

717-783-8143 for
Pennsylvania Department of Health
Newborn Screening and
Follow-Up Program

800-986-BABY (2229) for
information on finding a primary care
provider, getting health care coverage,
immunizations and tests for baby

800-986-KIDS (5437) for
information on finding a primary
care provider, getting health care
coverage, immunizations or tests
for your children

800-WIC-WINS (942-9467) to
obtain supplemental foods, nutrition,
education and breastfeeding
information

800-986-4550 for
information on services available for
children with special health care needs

800-4-A-CHILD (22-4453) to reach a
24-hour crisis hotline to offer support,
information and referrals on coping with a
crying baby and preventing child abuse

Additional Resources and Information

www.doh.pa.gov/newbornscreening

for information on newborn
screening and other Department
of Health programs



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