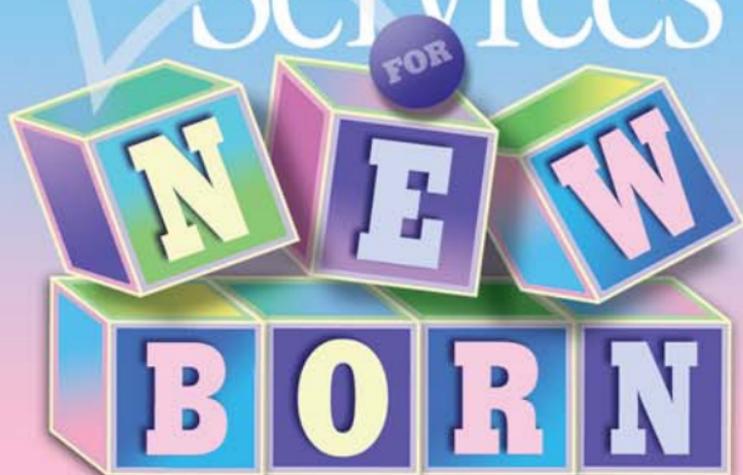


PENNSYLVANIA

Screening Services



BABIES

Protecting Babies

Preventing Problems

Screening Right After Birth

Starting Treatment Early

Pennsylvania Department of Health

This brochure describes special tests given to your new baby. These tests are called newborn screening tests. If the result of one of your baby's tests is "positive," this could mean a possible danger to your baby's health. Because of this, a repeat test needs to be done. This brochure gives information about where you can go for help.

A baby may appear to be healthy but may be born with a serious medical condition.

Today, we know a lot about helping babies with serious medical or hearing problems.

Many serious medical conditions can be identified with simple tests soon after a baby is born.

We know that the best way to help is to start treatment soon after babies are born.



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CHECKING Babies for Special **MEDICAL CONDITIONS**

What conditions are babies tested for?

Pennsylvania law requires babies to be tested for the 6 special genetic conditions listed below. The hospital where your baby is born may test for more conditions. Ask your healthcare provider about the additional tests.

1. Congenital Adrenal Hyperplasia (CAH)

(Kon-JEN-i-tal Ah-DRE-nal Hi-per-PLA-zhah) Babies born with this condition have a defect in an important substance (enzymes) the body needs. CAH can cause dehydration, shock and even death within a few days of birth. Medical problems are prevented when treatment is started soon after birth.

2. Congenital Hypothyroidism (CH)

(Kon-JEN-i-tal Hi-po-THI-roid-ism) Babies born with this problem do not have a thyroid hormone. They may look healthy. If not detected, the condition can cause poor growth and mental retardation. Giving the baby special medicine every day will prevent these results.



3. Galactosemia

(Gah-LAK-toe-SEE-mee-ah) Babies with this disorder cannot digest galactose. Galactose is a simple sugar found in breast milk, many formulas and milk products. This condition can harm the baby's eyes. It can cause serious liver and brain damage. Giving the baby a special milk-free diet as soon as the condition is found will prevent problems.

4. Maple Syrup Urine Disease (MSUD)

Babies born with MSUD cannot digest part of a food protein. Without treatment MSUD can cause severe mental retardation or even death shortly after birth. To prevent these results, babies are given a special formula and diet.

5. Phenylketonuria (PKU)

(FEN-nil-KEE-tone-u-ree-ah) Babies who are born with PKU cannot digest a different part of a food protein. Untreated, PKU causes nerve and brain cell damage, which can result in mental retardation. This damage can be prevented when a baby gets a special formula and diet.

6. Sickle Cell Disease and other Hemoglobin Diseases

Sickle cell disease is a group of genetic conditions that cause red blood cells to change shape. This leads to problems with blood circulation and anemia. Infants and children with sickle cell disease can die from lung and brain infections. Early treatment to prevent infections greatly reduces the chance of sickness or death. Sickle cell trait may also be identified through the screening. A baby with sickle cell trait has no known risk for related health problems. However, as an adult, he or she should get genetic counseling before deciding to have children.

The screening also tests whether your baby might have other less serious hemoglobin (blood disorder) diseases that can cause anemia or hemoglobin traits.



How is my baby tested?

The hospital or birth facility gets a drop of blood by pricking the baby's heel. The blood is placed on a special filter paper and mailed to a laboratory.

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

When is the testing done?

Usually the drop of blood is taken when the baby is 24 to 48 hours of age. This often happens just before the baby is discharged. The newborn screening test must be repeated if the baby is tested before he or she is 24 hours of age.

For how many conditions are babies tested in Pennsylvania?

By Pennsylvania law, babies are tested for 6 medical conditions. These conditions are only found in a few babies. By testing at birth, babies with these conditions can be found quickly to begin treatment. Early treatment prevents very serious medical problems or death. Ask your healthcare provider about other available tests called "supplemental screening."

My baby seems very healthy. Is the test still needed?

Yes. Most infants with these 6 conditions show no signs of illness immediately after birth.

If my baby has one of these conditions, can it be cured?

No. Your baby cannot be cured. When treatment is started very early in life, the medical problems related to the condition are often prevented.

Will I receive a report of the test results?

Test results are known within 7 to 10 days after the blood was taken. Test results are sent to



the birth facility and are placed in the baby's medical record.

If the test results show that there may be a problem, your baby's doctor will contact you. For this reason, it is very important that you give your birth facility the name, address and phone number of the doctor who will be caring for your baby. This will prevent delays in contacting you if further testing is needed.

Ask about the test results during your baby's regular checkup. Your doctor can call 717-783-8143 to get the results. This is the number for the Pennsylvania Department of Health Newborn Screening Program.

If my baby needs another test, does this mean that my baby has one of these conditions?

No, not necessarily. Another test may be needed because:

- The first blood sample was not large enough to complete the 6 tests.
- Your baby left the birthing facility before 24 hours of age.
- The first test showed a possible problem. A new blood sample is needed so the test can be repeated. Generally, if the results of the second screening test are not normal, the doctor will discuss the need for more testing.

If you are asked to have your baby retested, please have it done right away! Bring your baby back to the birth facility or your baby's doctor.

May I say NO to the tests?

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





CHECKING Babies for Hearing Loss

Hearing Screening

There are several ways to measure whether your baby can hear:

The Otoacoustic Emissions (OAE) test measures a tiny sound the ear makes when the baby is hearing properly.

The Auditory Brainstem Response (ABR) test measures how well the baby's nerve for hearing responds to sounds.

Both ways are safe. They take only a few minutes to perform while your baby sleeps.

If your baby passes the hearing screening

If your baby passes the newborn hearing screening, you do not need follow-up testing at this time – just remember that your baby's hearing does not have to be perfect to pass.

A small number of babies who pass the screening at birth can lose their ability to hear – suddenly or gradually - before they are one year of age or older.

If you have a family history of permanent childhood hearing loss, your baby should be tested every year.

Some babies may develop hearing loss later as a child. 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.

If your baby does NOT pass the hearing screening

There may be several reasons why babies do not pass the hearing screening:

- they have a hearing loss - either temporary or permanent;
- they are too active or do not sleep during the screening;
- the nursery is too noisy to get good screening results.

If your baby does not pass, you should come back for another hearing screening.

If your baby leaves the hospital without a hearing screening

The hospital tries to complete the hearing screen while your baby is in the hospital. If your baby is discharged before being screened, you should ask your primary care physician to make an appointment for a hearing screen.

A Pennsylvania Department of Health nurse may call to remind you that it is important to have this done.

Why screen my baby?

Hearing loss is found in between 1 and 3 out of every 1,000 newborn babies. More than half of babies born with hearing problems have no other health problems. They also do not have a family history of hearing loss.

If a newborn's hearing loss is not detected and not treated, your child may:

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



Your newborn baby cannot tell you if he or she is unable to hear. This is why your baby should be screened immediately after birth to check for hearing problems or as early as possible.



Where

CAN I GET HELP?

If you have any questions, 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, can:

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

Early Intervention is a support service made possible by government funds. The professionals help give your baby the best start in life.

**Call the CONNECT Line for
Early Intervention services:
(1-800-692-7288)**

Other sources of information:
your baby's doctor

Pennsylvania Department of Health's website:
www.health.state.pa.us

E-mail the Hearing Screening Program at
nbhs@state.pa.us



**An excellent source of information for all
pregnant women and parents of
newborns is the Healthy Baby help line.**

**If you don't have a doctor or can't afford
to pay for appointments, call the
Love'em with a Checkup Program.**

**Information and Referral Specialists can
connect you with a doctor in your area
and discuss available healthcare
coverage programs.**

**1-800-986-BABY
voice & TTY
(1-800-986-2229)**



Phone numbers to call for more information

1-800-986-BABY for information on finding a doctor, getting healthcare coverage, immunizations, and tests for baby.

1-800-986-KIDS for information on finding a doctor, getting healthcare coverage, immunizations, or tests for your children.

1-800-WIC-WINS to obtain supplemental foods, nutrition education and breastfeeding information.

1-800-986-4550 for information on services available for children with special needs.

1-800-4-A-CHILD 24-hour crisis hotline to offer support, information and referrals on coping with a crying baby and preventing child abuse.

Websites to visit for more information

www.health.state.pa.us for information on newborn screening and other Department of Health programs.

www.ins.state.pa.us for information on Pennsylvania Insurance Department's CHIP and adultBasic healthcare coverage programs.

www.dpw.state.pa.us for information on the Pennsylvania Department of Public Welfare's Medicaid healthcare coverage program.

www.compass.state.pa.us to apply for state social service programs online.

www.4woman.gov for information on breastfeeding.

www.acog.org for information on the American College of Obstetrics and Gynecologists.

www.aap.org for information on the American Academy of Pediatrics.

www.savebabies.org for information on screening tests and support groups.

www.marchofdimes.com for information.



Edward G. Rendell, Governor
Calvin B. Johnson, M.D., M.P.H., Secretary of Health