Making sure your Baby is Healthy

Early treatment is important! Without testing, it is impossible to tell if your baby has some health problems. If not treated, your baby could have serious problems like developmental delays, slow growth, and even death. With treatment, these may be prevented. The law says all newborns must be tested for over 60 rare but serious health problems.

- The Connecticut Newborn Screening Program began in 1964 with testing for two health problems. For 50 years, the CT State Public Health Laboratory has added tests. The program now checks for over 60 disorders.
- The Newborn Screening Program aims to test all babies born in CT, before they leave the hospital or health center, or within the first 4 days of life.
- The goal is to find babies with hidden problems early, so that they can get help before problems start. This often saves babies from permanent damage, health problems or death.
- For more information about the Connecticut Newborn Screening Program, call (860) 920-6628.

Please:

- Take this sheet home and read it carefully
- Pick a doctor for your baby before your baby is born
- Make sure the Laboratory Newborn Screening Tests are done before you leave the hospital
- Tell your nurse in the hospital if your baby will have a different last name after you go home
- Before you leave the hospital, make an appointment with your baby's doctor or other health care worker
- Give your phone number to the hospital and doctor in case they want to talk to you after you leave. If you don't have a phone, leave the number of a relative, friend or neighbor who can reach you
- Remember your baby must be screened through the Connecticut Newborn Screening Program, even if you choose to have additional screenings

Notes:

Keeping Connecticut Healthy
DPH
Connecticut Department of Public Health

This fact sheet is <u>important</u>! Please take it home and read it carefully.

Why does my baby need newborn screening tests? Without testing, it is impossible to tell if your baby has some health problems. If not treated, your baby could have serious problems like developmental delays, slow growth, and even death. With treatment, these may be prevented.

Who should be tested? Every baby should be tested.

When should it be done? Your baby should be tested more than one day after birth, but before the fourth day of life. The test should be done before your baby leaves the hospital or birth center.

How will my baby be tested? The hospital or birth center staff will prick your baby's heel and place a few drops of the blood on a special blood spot card. This special card is sent to the State Newborn Screening Laboratory for testing.

Can I say "no" to this test? Parents may refuse the test for religious reasons. You must sign a State of CT waiver to refuse the test.

What happens with the results? Results are sent to the hospital or center where the baby was born. Your baby's doctor will call you if they are not normal. This does not mean that your baby is sick. The doctor will discuss repeat testing with you. The doctor may discuss test results with one of the State Regional Treatment Centers for more follow up needs. **If your baby does have one of these conditions, it is important that treatment starts as soon as possible.**

What if I have more questions? For more information, call your baby's doctor, nurse, clinic staff, or the Laboratory Newborn Screening Program at (860) 920-6628. You can see the full List of Newborn Screening Tests, and more, at: www.ct.gov/dph/NBStestresultlevels.

For additional information about newborn screening, call (860) 920-6628.

What screening tests are done?

Biotinidase Deficiency. The body cannot make enough of the vitamin biotin. Taking biotin every day helps prevent bad skin rashes, sight and hearing problems, and brain damage.

Congenital Adrenal Hyperplasia. The body cannot make enough of some hormones. Taking the missing hormones helps prevent severe illness or death.

Congenital Hypothyroidism. This is caused by a lack of thyroid hormone. Taking the missing hormone helps prevent slow growth and developmental delays.

Galactosemia. The body cannot use a sugar that is in milk, infant formula, breast milk, and other foods. A special diet helps prevent damage to the brain, eyes and liver.

Hemoglobinopathies (Sickle Cell). This causes problems with red blood cells that lead to anemia, infections, pain, slow growth and death. Special medical care and penicillin help prevent these problems.

Hemoglobin Traits. The results tell if your baby is a Trait carrier of a hemoglobin disorder. This does not mean that your baby is sick. Your baby's doctor will give you important information.

Severe Combined Immunodeficiency Disorder. This condition was called the "Bubble Boy Disease". Children with this disease can't fight off infections. If found early, a bone marrow transplant often keeps a child healthy.

Amino Acid Disorders. Babies cannot break down some amino acids in foods like meat, milk, baby formula, and breast milk. When found early, treatment with special diets, vitamins, and medicine helps prevent serious problems. If untreated, this can lead to vomiting, diarrhea and developmental delays. **<u>Phenylketonuria (PKU) is an Amino Acid Disorder.</u>**

Fatty Acid Oxidation Disorders. Babies have trouble using fat for energy. This can lead to drowsiness, weak muscles, vomiting, low blood sugar, liver failure or death. A special low-fat diet and medicine help.

Organic Aciduria Disorders. Babies with one of these disorders cannot use certain amino acids and fatty acids. This can cause vomiting, poor feeding, low blood sugar, drowsiness, seizures, or death. Early treatment like a special low protein diet and/or medicine helps.

Parents may also get extra newborn screenings for other problems that are not part of the CT Newborn Screening Program. However, this extra screening may not be covered by insurance.

If you get additional screening, your baby must still be screened through the Connecticut Newborn Screening Program.

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Newborn screening tests could save your baby's life.