



Make Sure Your Baby is Healthy

Checklist:

- Ask your doctor, nurse or midwife about Newborn Screening (NBS)
- Pick a doctor for your baby before your baby is born
- Make an appointment with your baby's doctor before you leave the hospital
- Ask if your baby had the NBS test done before you leave the hospital
- Ask your baby's doctor for the results of your baby's NBS test
- Give a phone number where you can be reached after you leave the hospital
 - If you do not have a phone, give a friend's or family member's phone number
- Call the doctor if your baby:
 - has trouble eating
 - vomits often
 - has skin problems
 - is very sleepy all the time
 - looks sick



Newborn Screening (NBS) is important!

Babies with some health problems may not look sick when they are born but they can have trouble eating, gaining weight or have slow brain growth. They can also become very sick and sometimes die. Newborn Screening (NBS) helps find babies with certain health problems, so treatment can start early. Early treatment can help prevent serious illness and death.

Answers To Your Questions about Newborn Screening

Why does my baby need NBS?

- Without NBS, you cannot tell if your baby has certain health problems
- Connecticut NBS tests for over 60 health problems
- If one of these health problems is not treated, your baby may:
 - ◆ become very sick
 - ◆ grow poorly
 - ◆ have a physical disability
 - ◆ have brain damage
 - ◆ die
- With early treatment many problems can be prevented

Who should get the test?

- Every newborn baby should be tested

When is the test done?

- One to three days after birth

How is the test done?

- The doctor, nurse or midwife will take a few drops of blood from your baby's heel
- The blood is tested at the State Public Health Laboratory in Rocky Hill

Can I say "no" to this test?

- You can say "no" to the test for religious reasons
- You will be asked to sign a form that says you do not want your baby to be tested

How do I get the test results?

- Ask your baby's doctor for the results

More Answers to Your Questions

What does an abnormal result mean?

- It does not always mean that your baby is sick
- There are many things that can cause an abnormal result
- An abnormal result can happen:
 - ◆ if you took certain medicines while pregnant
 - ◆ if your baby was born early
 - ◆ if your baby's blood was collected too soon
 - ◆ if your baby had certain treatments while in the hospital
 - ◆ for many other reasons
- If your baby has an abnormal NBS test your doctor may:
 - ◆ examine your baby
 - ◆ ask about illness in your family
 - ◆ repeat the NBS test
 - ◆ order a different test
 - ◆ talk to a genetics doctor

If my baby does have one of these medical problems, what will happen?

- Your doctor may:
 - ◆ give your baby a special diet
 - ◆ give your baby medicine
 - ◆ start other treatment
 - ◆ have your baby see a special doctor



More Questions?

- Talk to your baby's doctor, nurse or midwife
- Call the Connecticut NBS Program at: **(860) 920-6628**
- Go to:
 - ◆ <http://savebabies.org/>
 - ◆ <http://www.babysfirsttest.org/>
 - ◆ <http://www.marchofdimes.org/baby/newborn-screening-tests-for-your-baby.aspx>
 - ◆ <http://www.ct.gov/dph/cwp/view.asp?a=3138&q=387742>



What does Connecticut NBS test for?

Adrenoleukodystrophy (ALD): The body builds up fatty acids. This can cause brain damage. Babies with **ALD** will be monitored by a doctor for many years and be treated if needed.

Amino Acid (AA) Disorders: The body cannot use proteins in some foods like formula, breast milk and meats. This can cause slow physical growth and brain damage. A special diet and medicine can help prevent these problems. The CT NBS program tests for many types of **AA** problems.

Biotinidase (BIO) Deficiency: The body cannot make enough of the vitamin biotin. This can cause skin rashes, weak muscles, hair loss, trouble seeing and hearing, and brain damage. A vitamin can help prevent these problems.

Congenital Adrenal Hyperplasia (CAH): The body cannot make enough of certain hormones. This can cause severe illness or death. Medicine can help prevent these problems.

Congenital Hypothyroidism (CH): The body cannot make enough thyroid hormone. This can cause growth problems and brain damage. Medicine can help prevent these problems.

Fatty Acid Oxidation (FAO) Disorders: The body has trouble using fat for energy. This can cause sleepiness, weak muscles, vomiting, low blood sugar, liver problems and death. A special diet and medicine can help prevent these problems. The CT NBS program tests for many kinds of **FAO** problems.

Galactosemia (GALT): The body cannot use a sugar that is in milk, infant formula, breast milk and other foods. This can cause eye and liver problems, brain damage and death. A special diet can help prevent these problems.

Hemoglobin (Hb) Disease: The body has a problem with red blood cells. This can cause anemia, infection, pain, poor growth and death. Medicine and special medical care can help prevent these problems. The CT NBS program tests for many types of **Hb** problems. Sickle cell is one type of **Hb** disease.

Hemoglobin (Hb) Traits: This test tells if your baby is a **carrier** of a red blood cell disease. This **does not** mean that your baby is sick. Your doctor will talk to you about what this means and may want another blood test.

Organic Acid (OA) Disorders: The body cannot use certain proteins and fats in foods. This can cause vomiting, poor feeding, low blood sugar, sleepiness, seizures and death. A special diet and medicine can help prevent these problems. The CT NBS program tests for many types of **OA** problems.

Severe Combined Immunodeficiency Disorder (SCID): The body cannot fight infection. This can cause serious illness and death. Bone marrow transplant is a treatment for **SCID**.