

Connecticut Newborn Screening Program
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New and Improved Newborn Screening Information for Parents

This fact sheet is **important!** 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 tested, your baby could have serious problems like developmental delays, slow growth, and even death. With treatment, those 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. The 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 next 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/NBS/newbornscreening.htm.

What screening tests are done?

Biotinidase Deficiency. The body cannot make enough of the enzyme 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 hormone helps prevent severe illness or death.

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

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

Hemoglobinopathy (Sickle Cell). This causes problems with blood circulation that lead to anemia, infections, pain, slow growth and death. Special medical care and medicine 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 brings a child healthy.

Amnio 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 medicines helps prevent serious problems. If untreated, this can lead to vomiting, diarrhea and developmental delays.

Phenylketonuria (PKU) or Amnio Acid Disorders.

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 Acidurias 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 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.

DPH

Newborn screening tests could save your baby's life.

Birthweights

Did you know that entering the wrong birthweight (BW) in Maven can cause a delay in identifying a baby with a serious and possibly life-threatening condition?

The NBS program uses BWs when interpreting results for Congenital Adrenal Hyperplasia (CAH) screening. Whether we call a NBS result normal or abnormal is directly related to the BW as entered in Maven.

Any change to a BW (or other demographic information) in Maven after a barcode has been printed must be reported to the NBS follow-up unit @ 860-920-6628

Reminder

Always double-check birthweights before exiting a newly created Maven record and before printing the barcode



These new black and white NBS tear-off sheets are being shipped out with NBS specimen card orders.

Please distribute to all new parents

(Feel free to use up your existing stock of color NBS brochures before switching to the tear-off sheets)

Available in English and Spanish

Connecticut Newborn Screening Program

Making sure your Baby is Healthy

Please:

- Take this sheet home and read it carefully.
- Make a class for your baby before you 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 test name after you get 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:

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Hospital Visits Resuming

Visits to birth hospitals, birthing centers and midwifery groups by the CT Newborn Screening Nurse Consultants are resuming. If your facility has not received a visit this calendar year, your nurse manager will be contacted in the near future to schedule one.

The purpose of these visits is to get to know our stakeholders, gain a better understanding of your NBS process, review QI measures, provide NBS updates and determine what your program needs from the CT NBS Program.

We encourage you to invite a few key staff members to this meeting, such as lead Maven data entry staff, laboratory staff, NBN/NICU nursing staff, neonatology staff, administrators, or anyone with a stake in newborn screening.