

KIDSNET

All babies born in Rhode Island are enrolled in KIDSNET, the Rhode Island information system that helps families and doctors make sure that children receive complete preventive health care. As your baby grows, your doctor and others will add your child's immunizations



and information from the following health screenings: developmental assessment, newborn hearing, newborn blood screening, and lead screening. Information from your baby's birth certificate and from the First Connections, Early Intervention, and WIC Programs is also included.

KIDSNET is used to remind families and doctors when immunizations, lead screenings, and other services are needed. If your child has been to different doctors, KIDSNET will keep track of all of his or her immunizations in one place. KIDSNET also helps to see whether all Rhode Island children are getting the care they need.

KIDSNET information is confidential and is protected under State and Federal privacy laws. Only the Health Department, doctors, nurses, and other approved professionals such as school nurses or the Head Start Program can see KIDSNET information. You have the right to see your

child's information. If you feel the information is incorrect or incomplete, you have the right to ask that it be changed. You also have the right to restrict who can see your child's information. For details about how to do this, call the HEALTH Information Line at **401-222-5960**, weekdays from 8:30am to 4:30pm.



Baby is Home!

Now that you and your baby are home, we want you to know what happens following the screening tests that were done while your baby was in the hospital. You can get the results of these tests from your doctor.

HEALTH Information Line

If you need more information about any of the newborn screening services or programs described in this guide, call the HEALTH Information Line at **401-222-5960**, weekdays from 8:30am to 4:30pm. Our team speaks English and Spanish.



Department of Health
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Providence, RI 02908-5097
www.health.ri.gov



Newborn Screening and Services

A guide to test results, programs,
and follow-up for your baby.



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Newborn Blood Screening

Your baby had a blood test in the hospital to check for metabolic (how the body digests food), endocrine (controls many body functions) and hemoglobin (blood) conditions. This blood sample will be stored until your baby reaches adulthood.

Sometimes this test needs to be repeated. This does not necessarily mean that your baby has a condition. If your baby's test needs to be repeated, a doctor or nurse will call and tell you. The repeat test should be done as soon as possible. It is best to have the repeat test done at the hospital where your baby was born, but you can go to the lab at any maternity hospital in Rhode Island. Results from these tests are reported to your baby's doctor. Tests are available for many conditions beyond those included in Rhode Island's Newborn Screening Program. These additional tests are available for a fee through other labs. If you would like to have your baby receive additional testing, talk to your baby's doctor.



Newborn Hearing Screening

In the hospital your baby's hearing was screened to measure how the ear responded to soft sounds. Sometimes the hearing screening needs to be repeated if the results are unclear. The Rhode Island Hearing Assessment Program will contact you if your baby needs to be retested. Bring your baby back to the hospital for the test as soon as possible.

If the test shows your baby might have hearing loss or your baby has risk factors for hearing loss, the Hearing Assessment Program will recommend that you take your baby to a hearing specialist (audiologist) for more testing.

If you have questions about your baby's hearing or test results, call the Hearing Assessment Program at **401-277-3700** voice/relay or **401-277-3701** TDD.

Your baby's doctor will continue to check your baby's hearing, speech, and language development along with other developmental milestones at each visit.



First Connections Program

While you and your baby were in the hospital, a nurse reviewed your pregnancy and delivery records. They looked to see if there were any reasons your baby's development could be delayed. Based on the review of your records, the nurse may have referred you to the First Connections Program.

The First Connections Program is a home visiting program for families with newborns and young children at no cost to the family. The program offers information on topics such as breastfeeding and nutrition, when to call you baby's doctor, and how to make your home safe for your baby. Home visitors provide support and link you to resources in your community that help you and your baby get off to a healthy start.

Birth Defects Program

Babies identified with birth defects in the newborn period are included in a Birth Defects Information System at the Department of Health. The program helps make sure that families and their children receive appropriate services and referrals. This information is also used to study patterns of birth defects. All information in the registry is confidential and is protected under state and federal privacy laws.

If you do not want your child's information entered into the Birth Defects Information System, you may either contact your child's doctor directly or call the HEALTH Information Line at **401-222-5960**, weekdays from 8:30am to 4:30pm. You also have the right to restrict the release of information on your child from the Information System and to chose to not be contacted by the Birth Defects Program.

Rhode Island screens babies for 28 health conditions and hearing loss. The conditions are grouped in the categories explained below, and a list of all the conditions is on the other side of this card. Many serious effects of these conditions can be prevented with early detection and treatment.

HEMOGLOBIN CONDITIONS: These conditions affect a baby's blood. They can lead to anemia (not enough red blood cells), slowed growth, pain, and damage to vital organs. Babies with hemoglobin disorders are treated with antibiotics because they can get very sick and even die from common infections.

ENDOCRINE CONDITIONS: Babies with endocrine disorders do not make enough of certain types of hormones. This affects their growth and development. These conditions are treated with special medication.

CYSTIC FIBROSIS (CF): Cystic Fibrosis affects the salt or water content of certain body fluids, such as sweat and mucus. This can lead to problems with breathing, digesting, and other body functions. Treatment may include medications, special diets, and other therapies.

AMINO ACID CONDITIONS: Babies with these conditions cannot digest certain amino acids (parts of proteins in our food). This can affect health, growth, and learning. Medications and special diets can help prevent these problems.

FATTY ACID OXIDATION CONDITIONS: Babies with these conditions have problems making energy from fat in the body or from food. Serious health problems can occur if these conditions are not treated. Medications, special low fat diets, and feeding a newborn at least every 4 hours can help prevent these problems.

ORGANIC ACID CONDITIONS: Babies with these conditions have problems digesting certain parts of protein from the food they eat. This can cause serious effects on health, growth, and learning. Early treatment with medication can help prevent these problems.

OTHER CONDITIONS: Babies with **biotinidase deficiency** can have problems with growth and development. This condition is treated with special medicine. Babies with **galactosemia** cannot use the sugars in milk, formula, and breast milk. If it is not treated, it can hurt the baby's eyes, liver, and brain. This condition is treated with special formula and diet.

Rhode Island screens babies for the following conditions:

HEMOGLOBIN CONDITIONS

Sickle cell anemia (SS)
Sickle/Beta-Thalassemia (S/Th)
Sickle/Hemoglobin C disease (S/C)

AMINO ACID CONDITIONS

Phenylketonuria (PKU)
Maple Syrup Urine Disease (MSUD)
Homocystinuria (HCY)
Citrullinemia (CIT)
Argininosuccinic academia (ASA)
Tyrosinemia type I (TYR1)

FATTY ACID OXIDATION CONDITIONS

Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
Long-chain 3-OH acyl-CoA dehydrogenase deficiency (LCHAD)
Trifunctional protein deficiency (TFP)
Carnitine uptake defect (CUD)

ORGANIC ACID CONDITIONS

Isovaleric acidemia (IVA)
Glutaric acidemia type I (GAI)
Hydroxymethylglutaric aciduria/
HMG-CoA lyase deficiency(HMG)
Multiple carboxylase deficiency (MCD)
Methylmalonic acidemia due to mutase deficiency (MUT)
Methylmalonic acidemia cblA and cblB forms (CBLA, B)
3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
Propionic acidemia (PROP)
Beta-Ketothiolase deficiency (BKT)

ENDOCRINE CONDITIONS

Congenital hypothyroidism (CH)
Congenital adrenal hyperplasia (CAH)

CYSTIC FIBROSIS (CF)

OTHER CONDITIONS

Biotinidase deficiency (BIOT)
Classical galactosemia (GALT)

Certain other conditions may be detected through newborn screening.

As testing methods improve, new conditions may be added to the list. The most current list is at www.health.ri.gov/genetics/newborn.php

For more information about newborn screening and specific conditions visit www.marchofdimes.com/pnhec/298_834.asp. You can also call the HEALTH Information Line at **1-800-942-7434**, weekdays from 8:30am to 4:30pm.

We speak English and Spanish.