

KIDSNET

KIDSNET is Rhode Island's information system that helps make sure that children receive complete preventive healthcare. All babies born in Rhode Island have health information included in KIDSNET. As your baby grows, your doctor and other authorized professionals may add your child's immunizations, height and weight measurements, nutritional status, medical conditions, and results of developmental, hearing, lead, and newborn blood screenings. Information from your baby's birth certificate and from Family Visiting, Early Intervention, Head Start, Early Head Start, Cedar, Asthma, Child Outreach, and WIC Programs is also included. If your child has been to different doctors, KIDSNET will keep track of preventive health services in one place.

KIDSNET information is confidential and is protected under state and federal privacy laws. Only the Rhode Island Department of Health, doctors, nurses, and other authorized professionals can see KIDSNET information. You have the right to see your child's information and to ask that incorrect or incomplete information be changed. You also have the right to restrict who can see your child's information. For details, call the Health Information Line at **401-222-5960 / RI Relay 711**, weekdays from 8:30 a.m. to 4:30 p.m.



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 / RI Relay 711**, weekdays from 8:30 a.m. to 4:30 p.m. Our team speaks English and Spanish.



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

Newborn Screening and Services

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



JULY 2020

Newborn Blood Screening

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

Sometimes, this screening test needs to be repeated. This does not necessarily mean that your baby has a condition. If your baby's screening needs to be repeated, a doctor or nurse will call and tell you. The repeat screening should be done as soon as possible. It is best to do this 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 screenings are reported to your baby's doctor. Screening is available for many conditions beyond those included in Rhode Island's Newborn Screening Program. These additional screenings are available for a fee through other labs. If you would like to have your baby receive additional screening tests, 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. What does it mean if your baby does not pass the hearing screen? It means that your baby needs further follow up. These tests will give you more information about your baby's hearing.

The birthing hospital will make an appointment for your baby to have a follow-up hearing screen. Bring your baby back to the hospital for the repeat screening, as soon as possible.

Follow-up testing is very important. *If your baby has a hearing loss it is important to find out early and get care to help with learning and language.* If the hospital does not give you an appointment, you can call Rhode Island Early Hearing Detection and Intervention (RIEHDI) at **401-277-3700** for further information. If your baby has risk factors for hearing loss, RIEHDI will recommend that you take your baby to a hearing specialist (audiologist) for more testing at seven to nine months of age. If you have questions about your baby's hearing screening results, please call RIEHDI at **401-277-3700**.

Your baby's doctor will continue to check your baby's hearing, speech, and language development.



Family Visiting

Being a parent is very rewarding and sometimes challenging. Having a little extra help and guidance can make it just a little easier to be a parent. Our Family Visiting Program will:

- Offer tips to help your baby grow up healthy
- Provide prenatal support and help with infants and toddlers
- Support you on how to manage a busy life
- Provide easy ways to connect and share with other moms

We will visit you at home or anywhere in your community. Every visit is about helping you help your baby develop and grow up healthy. To learn more or request a visit, **call 401-222-5960; or see www.FamilyVisitingRI.org.**

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 Birth Defects Program uses information in this system to 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 system 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 / RI Relay 711**, weekdays from 8:30 a.m. to 4:30 p.m. You also have the right to restrict the release of information on your child from the Information System and to choose to not be contacted by the Birth Defects Program.

Rhode Island currently screens babies for 35 health conditions, including hearing loss and critical congenital heart disease. In the summer of 2020, Rhode Island began screening for one new condition: Spinal Muscular Atrophy, a type of neuromuscular disorder. The conditions are grouped in the categories explained below. Early detection and treatment can prevent many serious effects of these conditions.

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 medicine.

CRITICAL CONGENITAL HEART DISEASE: Some babies are born with heart conditions that can cause low oxygen levels in the blood. We will do a painless test called "pulse oximetry screening" (also known as "pulse ox") to measure your baby's oxygen level.

CYSTIC FIBROSIS (CF): Cystic Fibrosis can lead to problems with breathing, digesting, and other body functions. Treatment can include medicines, special diets, and other therapies. Early identification is helpful, and there are new treatments.

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. Medicines 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. Medicines, special low fat diets, and feeding a newborn at least every four hours can help prevent these problems.

ORGANIC ACID CONDITIONS: Babies with these conditions have problems digesting protein from their food. This can cause serious effects on health, growth, and learning. Early treatment with medicine can help prevent these problems.

STORAGE DISORDERS: These babies have problems managing certain chemicals in their cells that build up to abnormally high levels. This can cause serious effects on health, growth, and learning. Early treatment can help prevent these problems.

NEUROMUSCULAR DISORDERS: Babies with these conditions have difficulty with muscle strength. This can lead to severe weakness. At first, they might have difficulty sitting or walking. Later, these conditions can affect breathing. Early diagnosis is helpful, as there are new treatments.

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. Babies with severe combined immunodeficiency are more at risk to develop infections. This condition is treated with a bone marrow transplant or other intervention.



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 <https://health.ri.gov/newbornscreening/blood/>. For more information about newborn screening and specific conditions visit www.marchofdimes.org/baby/newborn-screening-tests-for-your-baby.aspx.