Newborn Screening
and Services

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

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 immunization, 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, Career, 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.

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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 (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 help with hearing and language if the hospital does not give you an appointment, you can call Rhode Island Early Hearing Detection and Intervention (RIEHDI) at 401-222-5960 for more information. If you have questions about your baby’s hearing screening results, please call RIEHDI at 401-222-5960.

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

Rhode Island currently screens babies for 35 health conditions, including hearing loss and critical congenital heart disease. The conditions are grouped in the categories explained below. Early detection and treatment can prevent many serious effects of these conditions.

Newborn Blood Screening

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 from certain 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 formulas and diets. Babies with severe combined immunodeficiency are more at risk to develop infections. This condition is treated with a bone marrow transplant or other interventions.

Other Conditions: Babies with histidinemia 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 interventions.

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.