Congratulations!

Congratulations on the birth of your baby! This guide explains several early screening tests and services that Rhode Island offers for newborns. Before leaving the hospital, your baby will have these screening tests to detect serious conditions that may affect his or her health and development. All conditions identified through these screenings can be treated if found early. You do not have to pay for any of these screenings.

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.

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, Cradle, 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.
Newborn Hearing Screening

Before your baby goes home from the hospital, a few drops of blood will be taken from your baby’s heel. The blood will be screened for metabolic (how the body digests food), endocrine (how the body controls many functions), and hemoglobin (blood) conditions (refer to list for more details about these conditions). Newborn screening is required by law. Blood samples are stored until your baby reaches adulthood. To request, you must sign a waiver agreeing to undergo testing for any potential conditions.

The newborn screening should be done when your baby is at least 24 hours old. If your baby leaves the hospital before this time, you will have to bring your baby back for the screening. Sometimes, a screening may need 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 screening should be performed within the first 48 hours of life in the hospital where your baby was born, but you can go to the lab at any maternity hospital in Rhode Island.

Newborn Hearing Screening

Newborns are screened for about 20 to 40 different conditions. In Rhode Island, all newborns are screened for hearing loss and mental retardation conditions that may need to be treated. A hearing screen helps your doctor to check if your baby can hear sounds. The screening takes about 10 to 15 minutes.

If your baby has a hearing loss, your baby’s doctor will recommend that you follow-up hearing screening. Bring your baby back to the hospital for the repeat screening, as soon as possible. It 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 (RI EIDI) at 401-277-3780 for further information.

Rhode Island currently screens babies for 31 health conditions, including hearing loss and critical congenital heart disease. In October of 2018, Rhode Island will screen for three new conditions: Pompe, Adreno- and Mucopolysaccharidosis. 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. These affect their growth and development. These conditions are treated with special medicine.

Critical Congenital Heart Disease: Some babies are born with heart conditions that can be dangerous if not treated or if treatment is delayed. These conditions can cause low oxygen levels in the blood. We do a painless test called “pulse oximetry screening” (also known as “pulse ox”) to measure your baby’s oxygen level. You will be given the results of the pulse ox before you leave the hospital. A passing pulse ox screen does not pick up all heart conditions. If your baby fails the pulse ox screening, you will be discharged home. If you have any concerns about your baby’s oxygen level, you should talk to your baby’s doctor.

Cystic Fibrosis: Cystic Fibrosis affects the salt or water content of certain body fluids, such as sweat and mucus. This can lead to problems with breathing, digestion, and other body functions. Treatment may include medicines, 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 low fat 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 four hours can help prevent these problems.

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.rhodeisland.gov/newbornscreening/blood. For more information about newborn screening and specific conditions visit www.marchofdimes.org/baby/newborn-screening-tests-for-your-baby.aspx.

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