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, Cribs, 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 Blood 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 chart for more details about these conditions). Newborn blood screening is required by law. Blood samples are stored until your baby reaches adulthood. To refuse, you must sign a waiver agreeing that you understand the risk of not having the screening test done.

The newborn blood 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 needs to be repeated as soon as possible. It is too late 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, you will need to follow-up with their doctor.

Newborn Hearing Screening

During your hospital stay, your baby’s hearing will be screened to measure how the ear responds to soft sounds. How is the hearing screening done? A special machine called “pulse oximetry screening” (also known as “pulse ox”) to measure your baby’s oxygen level. 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 chart for more details about these conditions). Newborn blood screening is required by law. Blood samples are stored until your baby reaches adulthood. To refuse, you must sign a waiver agreeing that you understand the risk of not having the screening test done.

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Family Visiting

Being a parent is very rewarding and sometimes challenging. Having a little extra help and guidance can be a great comfort to all. 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.NewbornVisitingRI.org

Birth Defects Program

Babies identified with birth defects in the newborn period are included in a Birth Defects Information System at the Rhode Island 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.

How does the birth defect screening help your child? Your child will be included in the Birth Defects Information System, you may either contact your child’s doctor directly or call the Health Information Line at 401-222-5960; 83 Relay 711, weekdays from 8:30 a.m. to 4:30 p.m., to request a copy of the results of your child’s newborn screen. Your doctor will be notified of the results of the screening test.

Early Hearing Detection and Intervention (RIEHDI)

IF your baby has a hearing loss, it means that your baby needs to have a treatment plan designed to help him or her develop language skills (audiology) for more testing at 7 to 10 months of age. The RIEHDI Program will mail a letter to you with information on how to schedule this appointment. If you have questions about your baby’s hearing screening results, please call RIEHDI at 401-277-3788. 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. 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.

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. 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 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. For more information about newborn screening and specific conditions visit www.marchofdimes.org/baby/newborn-screening-tools-for-your-baby.asp.

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