Thinking Ahead

There’s so much to think about while you’re pregnant. Take a minute to learn about services your newborn will receive. At the hospital, your new baby will be screened (tested) for a variety of factors that may affect his or her health and development. All conditions identified through these screenings can be treated if found early. You will not have to pay for any of these screenings. We want your baby to get the best start possible, and these screenings are the first step.

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.

Newborn Screening and Services

A guide to test results, programs, and follow-up for your baby.
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, Adrenoleukodystrophy, and Mucopolysaccharidosis. The conditions are grouped in the categories explained below. Early detection and treatment can prevent many serious effects of these conditions.

**Newborn Blood Screening**

Before you and your baby go home from the hospital, a few drops of blood will be taken from your baby’s heel. This blood is used to screen for several serious conditions. The results will be reported to your baby’s doctor. Newborn blood screening is required by law. Blood samples are stored until your baby reaches adulthood. To release, you must sign a waiver stating that you understand the risk of not having the screening done.

Screening for other conditions not on the enclosed list is available for a fee through other labs. If you would like more information about additional screening tests, talk to a doctor or nurse while you are in the hospital.

**Newborn Hearing Screening**

Babies learn from the time they are born, and one of the ways they learn is through hearing. About 3–5 babies out of every 1,000 babies will have some form of hearing loss at birth.

Newborn hearing screening can detect possible hearing loss in the first days of your baby’s life. How is the hearing testing done? A small machine will be used to see if your baby responds to sounds. A small microphone will be put in your baby’s ear to measure how fast your baby responds to sounds. The test takes 10 to 15 minutes and does not hurt. You will receive the results verbally and in writing, before you leave the hospital. If your baby does not pass the hearing screening, it means that your baby needs further follow up. 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 screen, as soon as possible.

**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:

- **Provide easy ways to connect and share with other moms**
- **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**
- **Visit at your 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 / RI Relay 711 or see www.FamilyVisitingRI.org.

**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. Blood samples are stored until your baby reaches adulthood. To release, you must sign a waiver stating that you understand the risk of not having the screening done.

**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 be dangerous if not treated or if treatment is delayed. Some of these conditions can cause low oxygen levels in the blood. We will do a painless test called “pulmonary oximetry screening” (also known as “pulsox”) 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 does not pass the pulse ox screening, most tests will be done. If you have questions about pulse ox, you should ask the nurse or doctor caring for your baby. Also, if you have any concerns about the health of your baby after you go home, please talk to your baby’s doctor.

**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 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 development. This condition is treated with special medicine. Babies with biotinidase deficiency can have problems with certain parts of protein from the food they eat. This can cause serious effects on health, growth, and learning. Early treatment with medicine 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 medicine can help prevent these problems.

**Fatty Acid Oxidation Conditions**: These conditions are treated with special medicine.

**Amino Acid Conditions**: Babies with these conditions cannot digest certain amino acids (parts of proteins in our food). This can affect health, growth, and development. Babies with biotinidase deficiency can have problems with certain parts of protein from the food they eat. This can cause serious effects on health, growth, and learning. Early treatment with medicine can help prevent these problems.

**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, Adrenoleukodystrophy, and Mucopolysaccharidosis. 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 hemoglobin deficiency can have problems with growth and development. Some of these conditions are treated with special medicine. Babies with galactosemia cannot use the sugars in milk, formula, and breast milk. It is not treated, it can harm 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 another intervention.

**Certain other conditions may be detected through newborn screening. As testing methods improve, new conditions may be added to this list. The most current list is at www.health.ri.gov/newbornscreening/blod. For more information about newborn screening and specific conditions visit www.marchofdimes.org/baby/newborn-screening-tests-for-your-baby.aspx. You can also 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.**