

Frequently Asked Questions

What is the Newborn Screen?

The Newborn Screen is a special test used to test your baby for certain serious medical conditions. The goal of the screen is to try to identify babies who have these disorders before they get sick, and to help them get treatment as soon as possible. This test is sometimes referred to as the “PKU” test (an older term), by the medical community.

Is the Newborn Screen the same as the “PKU test”?

Yes, the Newborn Screen is often referred to as the PKU test, but this is an outdated term. PKU (PhenylKetonUria) was the very first condition screened for by newborn screening, back in the 1960’s and 70’s. Since this time many more conditions have been added to the test, which is why it should be referred to as the Newborn Screen.

How is the Newborn Screen performed?

The Newborn Screen is performed by pricking your baby’s heel and putting a few drops of blood onto special paper called filter paper. The filter paper is allowed to dry and is then sent to the State Health department. Once the blood gets to the Health Department, it is analyzed by the lab to identify babies who are at higher risk to have a medical condition. If the screen indicates your baby might have a medical problem, a member of the newborn screening follow-up group will call your baby’s doctor with the results. If we cannot identify the baby’s doctor, we may call you directly to get this information.

Will the test hurt my baby?

A nurse or medical assistant will use a small sterile lancet to prick your baby’s heel. The only pain the baby may feel is that of a quick prick, and it will go away quickly. Remember that the benefits of newborn screening, such as preventing learning delays and serious medical problems, greatly outweigh the discomfort the baby may feel due to the small heel prick.

Are there any side effects of the testing?

There is a very slight risk of infection of the puncture site or heel. The heel prick should be performed with a sterile lancet on a heel that has been cleansed, which means the risk for infection would be extremely small.

When does the Newborn Screening test happen?

The first test should be collected after the baby has had 24 hours of feeding. We collect the screen early to try to identify babies that have problems as soon as possible. In Maryland, we also recommend that babies get a second screen at the pediatrician’s office, to help identify disorders that may not have been identified on the first screen. This is usually collected between 7 days and 1 month of age.

What happens if my baby has a positive test?

If your baby has a positive test result, we attempt to contact the baby’s pediatrician or primary care doctor. We find out the doctor’s information and your baby’s name from the form connected to the blood spot that was filled out when the baby was in the nursery. It

is important to make sure the nurse in the nursery fills out the paper completely and has your most accurate contact information so that we can reach you easily if there is a problem. If we do not know who the baby's doctor is, we will call you directly to find out this information. If you do not have a working number listed, we will send a certified letter to your address.

Does a positive test mean my baby has the condition?

No. Sometimes the result will be what we call a "false positive". This means that the baby's initial results showed that they were at a higher risk to have the disorder, but the follow-up testing was normal. Other times the result does indicate the baby has a real problem.

Newborn screening is only a "screening" test, it is not a "diagnostic" test. This means that the test was made to find babies who may have a medical problem. If a baby has a positive screening test, he/she should get the recommended follow-up testing. If this test continues to indicate the baby has a problem, your doctor will refer your baby to a specialist for additional testing.

Depending on the results of the initial Newborn Screen, the follow-up unit may refer the baby immediately to a specialist or the emergency room.

My baby's follow-up testing was normal, is there anything else I need to do?

No, as long as all of the recommended follow-up tests were normal, no additional testing is needed. This means that the initial test was a "false positive" and your baby does not have the condition. It is important to make sure your baby has ALL of the recommended follow-up tests to be sure that he/she is healthy.

Do I get to see my baby's results?

We do not send the results directly to parents. However, you should talk to your baby's doctor and make sure he/she has a copy of the results. You can ask the baby's doctor to give you a copy of the results.

What if my baby looks healthy?

Most babies who have these conditions look healthy and act normally in the newborn period. The point of the test is to try to find babies that have these problems before they get sick. Just because your baby looks healthy does not mean he/she is healthy and it is important to listen to your doctor's advice.

No one in my family has these conditions, does my baby still need to be tested?

Yes! Most babies identified by Newborn Screening will not have a family history of the disorder. Many of them may even have healthy siblings. Having a normal family history does not necessarily mean that the baby will be healthy.

My baby was in the NICU (neonatal intensive care unit) for a while, do they still get the newborn screen?

Yes! All NICU babies still have newborn screening. The timing is usually slightly different. Babies in the NICU often get tested as soon as possible, they then usually get an additional test between 2-3 days of age, another around 10 days and, if they are still in the hospital, at one month of age. This schedule is not exactly the same in all hospitals around the state, so be sure to ask your baby's nurse in the NICU when your baby is scheduled to have his/her Newborn Screens.

Should all babies born in Maryland get the test?

Yes! All babies born in the state of Maryland should get a Newborn Screen.. Most babies get their first screen at the hospital and their second at the pediatrician's office. If you choose to deliver your baby at home it is important to talk to your pediatrician or family doctor about getting your baby a Newborn Screen as soon as possible.

Does the Newborn Screen test for all things that could make my baby sick?

No, the Newborn Screen tests only for specific disorders. The conditions on the newborn screen are decided by a group of specialists. They choose conditions that can be detected through the dried bloodspots used in newborn screening and that have a treatment. Unfortunately, there are some problems that can make children sick that we do not have treatment for, or are not able to detect using current newborn screening technology.

What conditions are on the Newborn Screen?

There are over 50 conditions on the newborn screen. Click here to learn more- [XXX](#)

How do they decide which conditions should be added to the Newborn Screen?

Each state makes its own decision about the conditions that are included in newborn screening. However, states base their decision on recommendations provided by national groups of specialists. The states consider things like: if treatment is available, if they can detect the condition in dried bloodspots, the cost of testing for the condition, and how good the lab is at picking up all children that have the condition (sensitivity) but not picking up those that do not (specificity).

Why does my baby have to have a repeat Newborn Screen?

In Maryland all babies should get a repeat screen. This should be done after your baby is 7 days of age or older.. This allows the lab to pick up some conditions that may not have shown up on the first screen. Other reasons babies may have a repeat screening are if something was a little off (abnormal) on the first screen and the lab wants to re-check a value or if the first sample was not able to be run because of a problem with the way it was collected (unsatisfactory specimen).

My baby was not born in Maryland, did they get a Newborn Screen?

Your baby probably had a Newborn Screen. You will need to check with the hospital where you baby was born. Most states screen for the same disorders, but not all states screen the same way. If your baby was born outside of the United States, he/she may or may not have had a newborn screen.

Who has access to my baby's test results?

The doctor caring for your baby, the hospital where your baby was born, and the people who work with the newborn screening laboratory at the state health department are the only people who have access to your baby's test results. If your baby needs to see a specialist, the results of the Newborn Screen will be provided to the specialist.

I do not know if I want my baby to have a Newborn Screen, what can I do about this?

Speak to your pediatrician and ask questions. Make sure you have all the information before making this important decision. Remember, most babies look healthy, even if they have a condition on the newborn screen that will cause them significant medical harm. If you decide you really do not want your baby to have newborn screening, someone from the state health department will also call you to discuss newborn screening. You do have the right to decline screening (this is called opting out). Remember, your baby is counting on you for this important decision.

What happens to the extra blood after the test?

The extra blood is stored by the Health Department. It is stored for several reasons, including if the lab needs to double check your baby's test result, or if you need it in the future. The lab also sometimes uses this extra blood to make sure their machines are working correctly (called quality assurance), or for the development of additional newborn screening tests so that we can help more babies in the future.

How long does the Health Department keep my baby's blood?

The State Health Department is required by law to keep your baby's sample for 25 years. This is for lab quality assurance, which means so the lab can be sure that their test results are correct and that they are reproducible (if they re-test the sample they will get the same results that they got the first time). If there is a question about the results of the newborn screen a physician can ask the lab to re-run the test for their patient even when that person is a young adult.