

Newborn Screening Conditions

Conditions identified by newborn screening may be passed down through families, even if there is no known family history of a condition.

Newborn screening conditions include:

- **“PKU” (Phenylketonuria)**
This condition started the field of newborn screening when a scientist invented a simple way to test hundreds of babies for this rare but debilitating condition. Babies with PKU cannot break down and use protein, such as the protein in milk. Untreated, PKU can cause severe damage to the brain and central nervous system.
- **Cystic Fibrosis**
A disease that affects the lungs, pancreas and digestive system.
- **Sickle Cell Anemia**
When the body’s red blood cells have abnormal shapes and are less able to deliver needed oxygen to the body’s tissues.
- **Many More Conditions**
Find conditions screened in your state: newsteps.org/data-resources/state-profiles

The US Department of Health and Human Services advises that states screen for a number of conditions via the Recommended Uniform Screening Panel. All states screen for most of these conditions. Differences among states are due to laws, funding, financial costs, and availability of tests and treatment.

Options for Parents

Every state requires its newborns to be screened. Some states allow parents to refuse for religious or other purposes, however this decision should always be discussed with a health professional since this test is intended to identify disabling or fatal conditions that are not necessarily apparent at birth.

Supplemental Screening

If your state does not screen for a particular condition, there are several private companies and universities that provide these services at an additional cost. For more information, go to: BabysFirstTest.org/newborn-screening/conditions#2

Screening Analysis

State public health laboratories are responsible for screening almost all (99%) of the nearly four million babies born in the United States each year. These state-run laboratories have trained scientists and highly-advanced instruments needed to detect newborn screening conditions.

Public health laboratories detect some conditions by looking directly for changes in your child’s genes. In most cases, however, they look for unusually high or unusually low levels of body chemicals like certain hormones or amino acids.

Learn More

For more information about newborn screening and how it can protect your child, contact the Association of Public Health Laboratories at newborn.screening@aphl.org or visit APHL.org/NBS

Learn More

Scan the QR codes below with your phone camera to open the resources.

Hear from other parents about the importance of newborn screening:



Find out what conditions are screened for in your state:



Protect Your Newborn’s Health With Newborn Screening



Nearly 4 million babies are screened annually in the US and thousands are saved from death or disability.

Your child could be one of them.

Newborn screening begins with a small heel prick to collect a few drops of blood on a filter paper card within the first 48 hours of life. The hospital or licensed midwife will send the card to a laboratory where scientists look for signs of rare but serious conditions that might not be noticeable by you or even by your baby's healthcare provider. When these conditions are detected and treated at birth, most babies grow up to lead healthy lives.

Your baby will also be screened for heart defects and early hearing loss at the hospital. These tests are simple and painless.

- ✓ Before you leave the hospital or birthing center, make sure to ask the nurse if your baby has had their newborn screening tests.
- ✓ Ask about your baby's newborn screening results at your baby's first check-up.

Most babies with a condition detected through newborn screening have no known family history of the disorder and appear to be perfectly healthy at birth. Newborn screening allows these infants to be identified and treated before they get sick, preventing serious health problems or even death. Every year in the US over 12,000 babies' lives are saved or improved through screening.



**You know your baby's length and weight.
Do you know their newborn screening results?**

A Coordinated System for Protecting Babies

Newborn screening is more than a series of tests. It's a closely coordinated system that involves maternal and child healthcare providers, public health laboratories and geneticists, all working together to protect babies' health.

When a baby tests positive for a newborn screening condition, this team works quickly to alert parents and the baby's healthcare provider to ensure the right follow-up treatment for the baby. For newborn screening to meet its goal of timely detection and treatment, the process must run as smoothly as possible; conditions found early but not treated can have life-long negative health effects. In contrast, with timely follow-up treatment, most babies live a full and healthy life.

Newborn Screening Varies by State

Newborn screening practices vary across states. Some state programs perform a second screen on newborns during the second week of life. This test is typically done during your baby's first visit to the pediatrician or other family healthcare provider.

What If My Baby Tests "Positive"?

If your baby has a positive screen, or test result, it may not mean that your baby is sick, but it is important that you take these results seriously.

If you receive a phone call from your state public health program or healthcare provider, make sure to have your baby evaluated immediately so he or she can get appropriate treatment and follow-up care if necessary.

Early identification and early treatment are key to the success of newborn screening.

The wonderful thing about my daughter's newborn screening story... there is no story.



"Because of newborn screening, Maren did not suffer from a metabolic stroke which happens to most babies with her condition. She did not require emergency life-saving measures in the first weeks of her life, as is also typical with babies who are left undiagnosed. Due to the process of newborn screening, we have not been a family in crisis, but instead, we have been a family empowered with knowledge.

Newborn screening showed that my daughter has a very serious and complicated disease called "propionic acidemia" that would need immediate intervention to avert a permanent life-altering crisis or death. I would say that I can't imagine what would have happened if she was not screened. But the sad truth of the matter is that I know exactly what could have happened if her condition was not screened for. I have gotten to know too many parents whose babies have been compromised and forever changed with neurological deficiencies, brain damage, heart problems, coma, developmental delays, loss of motor skills, the need for permanent feeding tubes or some other equally devastating event.

Because of newborn screening my daughter is developing on time and normally. She has been given the best start in life. Now, whenever I see a pregnant woman, I stop and take a quick moment to say, "Make sure you ask about your baby's newborn screening. It saves lives.

It saved my daughter's."

— Honey Stecken, South Fork, CO
Parent of child with propionic acidemia