

## Newborn Screening Conditions

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

Examples of 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.

The U.S. Department of Health and Human Services’ advises that states screen for 31 conditions, including hearing loss and critical congenital heart disease. All states screen for at least 29 of these conditions. Differences among states are due to laws, funding, financial costs, and availability of tests and treatment. Find the conditions screened in your state at [www.babysfirsttest.org/newborn-screening/states](http://www.babysfirsttest.org/newborn-screening/states).

**newborn screening**  
50 years of saving babies’ lives

## 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 always should be discussed with a health professional since this test is intended to identify disabling or lethal conditions in your baby.

## 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 [www.babysfirsttest.org/newborn-screening/conditions#2](http://www.babysfirsttest.org/newborn-screening/conditions#2).

## Where Your Baby’s Test Card is Analyzed

State public health laboratories are responsible for screening nearly all (97%) of the over 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 genetic mutations. In most cases, however, they look for unusually high or unusually low levels of body chemicals like certain hormones or amino acids.

## For More Information

For more information about newborn screening and how it can protect your child, contact the 50 Years of Saving Babies’ Lives campaign, 240.485.2717, [newborn.screening@aphl.org](mailto:newborn.screening@aphl.org), [50YearsSavingBabies.org](http://50YearsSavingBabies.org).



These professional healthcare provider, research and health advocacy organizations endorse the information on newborn screening in this brochure:

The American Academy of Pediatrics  American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN™

March of Dimes  march of dimes

Genetic Alliance/Baby’s First Test  baby’s first test

The American College of Obstetricians and Gynecologists supports the information on newborn screening in this brochure.



## What’s the Best Thing You Can Do to Protect Your Newborn’s Health?



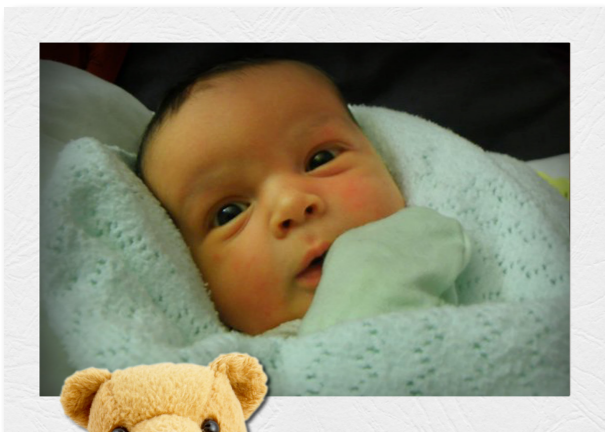
Newborn Screening  
50 Years - Saving Babies’ Lives



[www.aphl.org](http://www.aphl.org)

## More than 4 million babies are screened annually in the U.S. 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 24-48 hours of life. The hospital or licensed midwife will send the card to a laboratory where scientists will look for signs of rare but serious conditions that might not be noticeable by you or even by your baby's healthcare provider(HCP). When these conditions are detected and treated at birth, most babies develop normally and lead healthy lives.



Your baby also may receive hearing screening and screening for heart disease 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 her newborn screening test.
- ✓ Also, 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 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 U.S. over 12,000 babies' lives are saved or improved through screening.



**You know your baby's length and weight.**

**Do you know your baby's newborn screening results?**

### A Coordinated System Protecting Babies

Newborn screening is more than a series of tests. It's a closely coordinated system that involves maternal and child health care providers (HCPs), public health laboratories and geneticists, all working together to protect babies' health. When a baby tests positive for a newborn screening condition, this team moves fast to alert parents and the baby's healthcare provider to quickly secure the right follow-up treatment for the baby. In newborn screening there can be no delays, as conditions found early but not treated can negatively affect a child's mental or physical health for a lifetime. In contrast, with timely follow-up treatment, most babies live a full and healthy life.

### Newborn Screening Varies by State

Newborn screening practices vary among 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 does 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 health care provider, make sure to have your baby re-tested 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 is that 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, Colorado  
Parent of child with propionic acidemia