

Title: Newborn Screening for Cystic Fibrosis

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Abstract: Cystic fibrosis is a genetic, life-long disease of the lungs and digestive tract with many complications. Early diagnosis of cystic fibrosis through neonatal screening improves nutrition, improves growth, and healthier lungs.

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Are there any negatives to screening my newborn for cystic fibrosis?

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The key here is not to worry if your baby screens positive for cystic fibrosis...Not every baby with a positive screening will have cystic fibrosis! All babies with a positive newborn screen will have the salts measured in their sweat to see if they have the disease for sure.

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How do I know if my baby was screened for cystic fibrosis?

Not all states screen their newborns for cystic fibrosis. You can contact your local pediatrician to find out if your state does newborn screening for cystic fibrosis.

This patient education tool was prepared by:

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# Newborn Screening for Cystic Fibrosis

## So what is Cystic Fibrosis?

Cystic fibrosis is a disease that a person will have his or her entire life. It is an inherited disease that causes problems with breathing, digestion, and lots of infections. People with cystic fibrosis have a gene that makes the wrong protein and causes super thick, sticky mucus in the lungs and digestive track. This thick, sticky mucus causes the following problems:

- Cough
- Troubles breathing
- Lots of bad lung sicknesses
- Poor growth (short and skinny) because the person can't get the right energy and nutrition out of the food he or she eats
- Problems getting vitamins from food into the body
- Greasy diarrhea that floats in the toilet
- Boys with cystic fibrosis will not be able to have kids
- Salty tasting sweat

## How is it diagnosed?

- Sweat test—>Look for lots of salt in the person's sweat. People with cystic fibrosis have lots of salt in their sweat
- Genetic testing—> Blood test to look for the bad gene



## What is newborn screening for cystic fibrosis?

- A drop of blood is always taken from the newborn a couple days after birth to look for many bad diseases.
- From this blood doctors look for a specific chemical and problematic gene to spot babies that may have cystic fibrosis.

## What are the benefits of newborn screening?

In the past, doctors have waited until children show signs that they have cystic fibrosis before testing them. With newborn screening, doctors know the newborn has cystic fibrosis BEFORE the disease causes problems. This way they can start treatment early to avoid or put off the problems of cystic fibrosis. Compared to children diagnosed later, newborns diagnosed with cystic fibrosis have:

- Improved nutrition
- Improved growth
- Healthier lungs
- Less trips to the hospital
- Healthier bodies