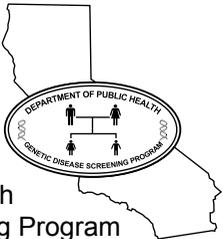


Cystic Fibrosis (CF) in Babies



State law requires that all babies have the newborn screening test before leaving the hospital. A few drops of blood were taken from your baby's heel and tested for certain diseases. Your baby tested positive for CF and now needs more testing as soon as possible to confirm this. Your baby needs to be seen by a CF specialist at a CCS-Approved Cystic Fibrosis Center.

California Department of Public Health



Newborn Screening Branch
Genetic Disease Screening Program
www.dhs.ca.gov/nbs

Why Does My Baby Need More Testing?

Your baby's test showed a "positive" result for cystic fibrosis. More testing is needed to confirm the baby has cystic fibrosis (CF).

Babies can look healthy at birth and still have CF. If untreated, this can cause severe health problems.

What Is CF?

CF is an inherited disease that affects many organs, most commonly the lungs and digestive system.

Symptoms of CF include:

- very salty sweat
- repeated bronchitis
- frequent coughing
- digestive problems including not gaining weight normally and loose, oily, foul-smelling stools
- other health problems

Early detection and appropriate treatment helps decrease some of the symptoms experienced by individuals with CF. Current treatments include nutritional supplements, chest physiotherapy, and medications.

To confirm the diagnosis, your baby will need to have a sweat test done. A sweat test is painless. It measures the amount of salt in the baby's sweat. Babies with CF will have higher amounts of salt in their sweat.

How can I prepare for a sweat test?

- Starting 2 days before the test and on the day of the test, give your baby 1/8 teaspoon of salt per day. The salt can be added to formula, expressed breast milk, or a moist nipple and given throughout the day. The extra salt helps make sure that the sweat test result is accurate.

- 3 hours or less before the test, breast or bottle feed your baby. This will help your baby make enough sweat for the test.

More than one sweat test may be needed. Follow these steps before each test unless your doctor gives you different instructions.

What is the Treatment for CF?

CF is a life-long condition for which there is currently no cure. Once a child is found to have CF, treatment to prevent malnutrition and minimize lung damage can be started immediately, even if there are no symptoms present.

Treatment typically includes nutritional support, including pancreatic enzymes and vitamins, respiratory therapy, and aggressively treating lung infections when they arise. New treatments are being explored and significant breakthroughs have been made in recent years.

The best way to help your baby is to learn as much as you can about the disease and to make sure your baby gets the best health care possible. Cystic fibrosis affects different people in different ways. The CF Center will provide education and materials so that families can learn about CF and its therapy.

A CF center is a specialized center with a team of experts trained in the treatment of CF. They can provide your child with the special care needed to treat CF.

How Does a Baby Get This?

Usually, a baby with cystic fibrosis inherited two genes, one from each parent, that do not work correctly. Each parent carries one working and one non-working gene for

cystic fibrosis for a baby to inherit this disease. Parents typically do not have the disease.

How Common is Cystic Fibrosis?

About 1 in 5,800 babies in California (about 100 babies a year) are born with this disease.

Anyone can have cystic fibrosis. It is found in all ethnic groups.

What Happens Now?

The doctor will advise you as to what steps need to be taken. The NBS Program strongly recommends that newborns with positive screening results be referred to a California Children's Services (CCS)-approved Cystic Fibrosis Center for a diagnostic evaluation. More testing, including a sweat test, will be needed.

Who Will Pay for the Diagnostic Evaluation and Treatment if Needed?

All newborns referred to a CCS-approved Cystic Fibrosis Center by the NBS Program are eligible for a diagnostic evaluation through the Cystic Fibrosis Center regardless of income. You will be asked to complete an application form.

Where Can I Get More Information?

Call the doctor or the Newborn Screening staff listed below for any questions or concerns.

For more information about CF, please visit the Cystic Fibrosis Foundation website at www.cff.org or the Cystic Fibrosis Research, Inc. website at www.cfri.org.

