

Family action sheet for cystic fibrosis (CF)

If a newborn blood screening result shows that your baby could have a serious condition called cystic fibrosis (CF) or a related disorder, this result requires further testing.

All babies born in California have a routine blood screen shortly after birth. The goal of this newborn screening is to find those at risk for serious medical conditions. Babies can look healthy at birth and still have one of these conditions. Babies with these conditions benefit from early diagnosis and treatment.

What is cystic fibrosis or CF?

Cystic fibrosis is a condition that changes the mucus on the lungs, digestive system, and other organs and tissues. Mucus covers those areas to keep them moist. With cystic fibrosis, it goes from thin and slippery to thick and sticky.

This thick mucus can build up in the lungs causing breathing difficulty and frequent infections.

Babies with cystic fibrosis cannot digest food adequately. This can lead to poor growth.

Cystic fibrosis is an inherited condition. This means that it is passed down to children from parents. The parents may or may not have the disease themselves.

Is there treatment for cystic fibrosis?

Yes, there are treatments for cystic fibrosis. Early detection and treatments and ongoing monitoring by a specialist help people manage and live well with the disease.

Current treatments include medications, high-calorie diet, and airway clearing therapy.

Newborn screening takes blood from a newborn's heel to screen for medical conditions



Next steps

1. Your baby's medical provider will refer you to an experienced specialist that treats cystic fibrosis.

More tests are needed to find what treatment or monitoring will be needed for your baby.

2. Work closely with your baby's medical provider and the specialist and follow their recommendations

It is important that you keep all appointments and start a treatment plan if instructed.

Where can I get more information?

Your baby's medical provider or cystic fibrosis specialist is the best person to teach you about cystic fibrosis. Find more information at these websites:

• Baby's First Test

(<https://www.babysfirsttest.org>). Type "CF" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español"

• Health Resources & Services Administration

(<https://newbornscreening.hrsa.gov/conditions/cystic-fibrosis>)

