



For Parents of Babies who are Cystic Fibrosis (CF) Carriers

California
Department of
Public Health



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

For parents of babies who are Cystic Fibrosis (CF) carriers

The Newborn Screening Test showed that your baby is a Cystic Fibrosis (CF) carrier. Being a carrier is not an illness and does not affect your baby's health. CF carriers do not need special medical care or attention, but there are a few key things you should know. CF is an inherited genetic disorder. This means that the CF gene was passed down from the parents to the baby.

What are genes and what do they do?

Genes are the set of instructions that tell our body how to work. These instructions come from our parents. Every newborn receives two copies of all the genes in their body — one copy of genes from mom, and one copy from dad. Sometimes a non-working gene can be passed from parent to child. When the child receives one non-working gene and one working gene, the child is a carrier of the disorder.



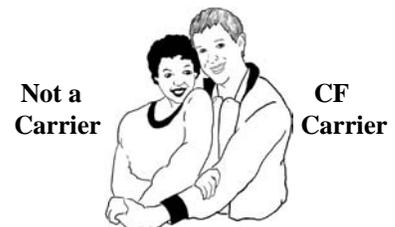
- 1 -

What is a Cystic Fibrosis carrier and how does it happen?

A carrier is someone who has one non-working CF gene inherited from one parent. This means that the carrier's second copy of the gene is working properly which lets their body function correctly.

When one parent is a CF carrier, there is a 50% chance with each pregnancy that the baby will also be a CF carrier. If this is the case, the baby will be healthy, just like the parent who is a CF carrier.

When One Parent is a CF Carrier



50%
Chance



Not a Carrier/
No CF

50%
Chance



CF Carrier

Chances apply to each pregnancy.

- 2 -

If our baby is healthy, why should we be tested?

If you plan to have more children in the future, both parents should consider getting CF carrier testing. Because your child is a CF carrier, at least one parent is also a CF carrier. However, it is also possible that both parents may be CF carriers. If both parents are found to be carriers, there is a 25% chance of having a child with CF in each future pregnancy. In this case, genetic counseling is recommended to explain how the pregnancy might be affected and what prenatal testing options are available.



- 3 -

Remember - your baby is healthy

Being a CF carrier is not a disease. It will never change into a disease. However, in very rare cases, a baby who appears to be a CF carrier could have CF due to a non-working CF gene that Newborn Screening could not detect.

So, it is important to pay attention to any of these changes in your baby's health:

- chronic breathing or digestive problems
- not gaining weight, or
- frequent respiratory illness (e.g. coughing, congestion, wheezing)

Contact your baby's doctor if any of these problems occur.



What should we do now?

- For more information, call the Newborn Screening CF Carrier Follow-Up Program, toll-free at **(800) 793-1313**.
- Tell your baby's doctor that your baby was identified as a CF carrier.
- Contact your doctor about having CF carrier testing for both parents.

- 4 -

How is having CF different from being a carrier?

CF occurs when the baby receives two copies of the non-working CF gene, one from each parent. This means the baby does not have any working copies of the CF gene, and will have the disorder.

Most commonly, having CF can lead to lung and digestive problems and requires medical treatment.

- 5 -