



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 does not affect your baby's health. The baby does not need further CF testing. 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.



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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.

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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.



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Remember - being a carrier will not make your baby sick.

CF carriers do not have cystic fibrosis or health problems caused by CF.

If you have any concerns about your baby's current health, please contact your baby's doctor.

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. The Newborn Screening CF Carrier Follow-up Program can assist your doctor with information about laboratories and test methods for parent testing.
- Keep this pamphlet with your child's medical records. When your child is older, tell him or her that he or she is a CF carrier and the gene can be passed on to his or her children. A doctor or genetic counselor can also be contacted to discuss what it means to be a carrier.



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What is Cystic Fibrosis and how does it happen?

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.

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