Understanding Your Baby's Cystic Fibrosis (CF) Test Results

In California, all newborn babies are screened for many different disorders shortly after birth. The screening tests for cystic fibrosis (CF), a genetic condition that is passed down from parents to their children. The screening test also identifies babies who are CF carriers. **Your baby had this test, and the results showed that your baby is a CF carrier.**

A CF carrier is someone who has one CF gene that works properly and one CF gene that does not. Because one gene works well, your child probably won't have serious health problems related to being a CF carrier.

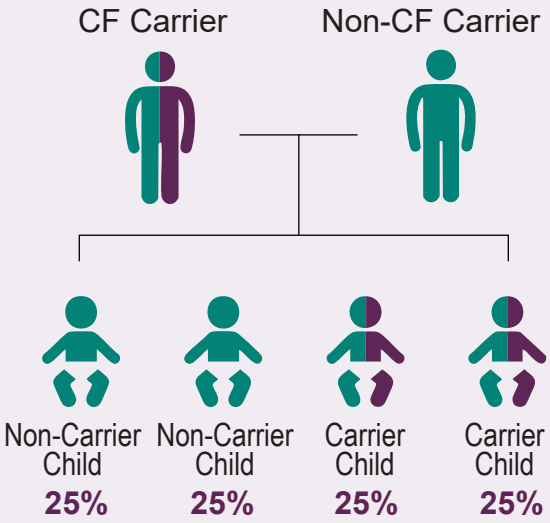
What is cystic fibrosis?

Cystic fibrosis occurs when someone has two CF genes that don't work properly. CF affects the cells that produce mucus, sweat and digestive juices. Having CF can lead to serious lung and digestive problems and requires long-term medical treatment. Individuals from all ethnic and racial backgrounds can have CF or be CF carriers.

What are genes?

Genes are instructions that control how a baby looks and how their body works. These genes come from the parents. Most of the time, babies get two sets of genes - one from each parent. When a child receives one CF gene that works well and one CF gene that does not, they are a CF carrier. **If a baby is a CF carrier, one or both of their parents may also be carriers who could pass their non-working CF gene to future children.**

When one parent is a CF carrier and the other parent is not a carrier



There's a:

- 50% (2 in 4) chance their child will not be a CF carrier and will not have CF.
- 50% (2 in 4) chance their child will be a CF carrier and most likely not have CF.

CDPH California Department of Public Health

California Department of Public Health
Newborn Screening Program (www.cdph.ca.gov/NBS)

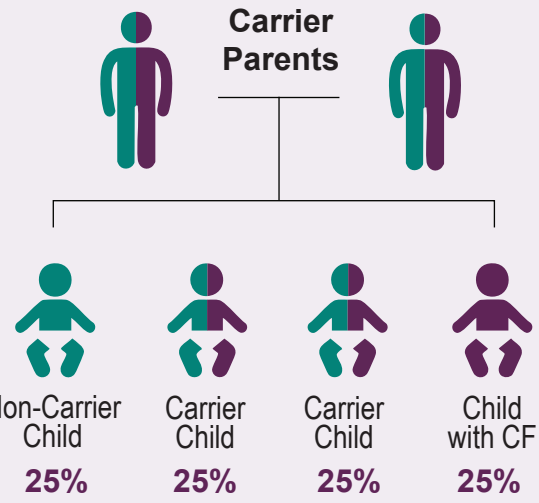
What do parents need to know?

When both parents are CF carriers, there's a 25% (or 1 in 4) chance with each pregnancy that their baby will get CF. When only one parent is a CF carrier, there is a 50% (or 1 in 2) chance with each pregnancy that their baby will be a CF carrier. **If you plan to have children in the future, CF carrier testing is available to both parents.** A genetic counselor can answer all your questions. They will be available to provide more information about CF, what it means to be a CF carrier, and how parental testing may identify the possibility of CF in future pregnancies.

Will I need to tell my child in the future?

When your child is older, it is important for them to know that they are a CF carrier and could pass the non-working gene to their future children. You should include information about your child being a CF carrier in their medical records and communicate this to their healthcare providers.

When both parents are CF carriers



There's a:

- 25% (1 in 4) chance their child will not be a CF carrier and not have CF.
- 50% (2 in 4) chance their child will be a CF carrier and most likely not have CF.
- **25% (1 in 4) chance their child will have CF.**

Note on screening tests

Screening tests are accurate but are not designed to detect all conditions a baby may have. Contact your baby's health care provider if you have questions or concerns about their health.

For more information

- Call this toll-free number: 1 (800) 793-1313, Monday through Friday, 9:00 am - 5:00 pm, for more information or to request to speak with a genetic counselor.
- Ask your baby's health care provider about CF carrier services and parent testing at your next appointment.
- Visit the Cystic Fibrosis Foundation (www.cff.org/intro-cf/carrier-testing-cystic-fibrosis).