Children who are carriers for CF should grow and develop normally.

Children who are carriers for CF do not typically have symptoms of Cystic Fibrosis or CF disease.

Children who are carriers for CF do not require medical treatment for CF. Your child can pass their nonworking CF gene on to their children.

Your child's future children could have CF if their mate also is a carrier for CF. Your child should be made aware of this risk when they are old enough to understand genetics and begin to plan for a family.

Cystic Fibrosis occurs:

1 in 3,000 Caucasian births

1 in 30 people are carriers for CF

30,000 people in the United States have Cystic Fibrosis

More than **45%** of the CF population is age 18 or older and the average life expectancy continues to increase.

Additional Resources

Arkansas Cystic Fibrosis Care Center:
www.arkansasCF.com

Cystic Fibrosis Foundation:
www.cff.org

Genetics Home Reference: Cystic Fibrosis
www.ghr.nlm.nih.gov/condition/cystic-fibrosis

Cystic Fibrosis in Diverse Communities:
www.lung.org/lung-disease/cystic-fibrosis/

Clinical and Functional Translation of CFTR:
www.cftr2.org

Carrier of Cystic Fibrosis

What you need to know

Arkansas Children's
HOSPITALS · RESEARCH · FOUNDATION

#1 Children's Way | Little Rock, AR 72202

For more information or questions, please contact the Cystic Fibrosis Center or the Genetics Department at Arkansas Children's Hospital

Cystic Fibrosis Center: (501) 364-1006
Genetics Department: (501) 364-2966

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Arkansas Children's Hospital is an accredited Cystic Fibrosis Care Center by the National Cystic Fibrosis Foundation

Congratulations on the birth of your baby!

Your baby had a positive newborn screen for cystic fibrosis (CF). Further testing shows your child is a carrier for the CF gene.

This brochure is to inform you what it means to be a carrier of the CF gene, provide resources for additional information, and help guide your next steps.

If you have more specific questions, talk with a CF newborn screening expert such as a doctor, nurse specialist, or genetic counselor.

What is Cystic Fibrosis?

Cystic Fibrosis is a genetic, chronic disease that affects the respiratory, digestive, and reproductive systems.

Cystic Fibrosis is inherited – just like eye color, hair color, or height. We all have two copies of the CF gene. To have CF, a person must inherit 2 copies of the CF gene that do not work properly– one from each parent. If a person only receives one non-working CF gene, then they are called a carrier of the CF gene.

What does it mean to be a carrier of Cystic Fibrosis?

Your child was found to have one non-working copy of the CF gene and a negative sweat test, so they do not have CF. They are a carrier for CF.

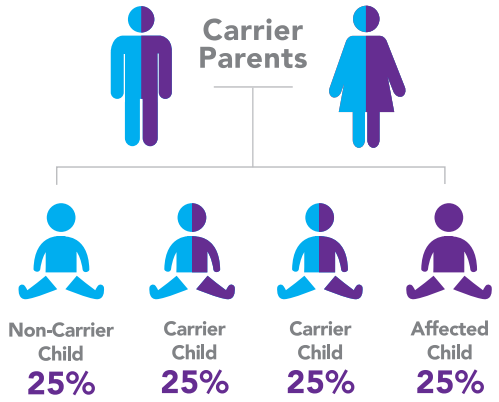
This means either you or your partner are also a carrier of the CF gene. When only one parent is a carrier, the chances of having children with CF are low.

- 50% will be a carrier for the CF gene
- 50% will not have the CF gene

However, it is possible both you and your partner are carriers of the CF gene even though your child does not have CF.

It is important to know each time two CF carriers have a child, their child has a:

- 25% chance of having CF
- 25% of not having CF
- 50% chance of being a carrier



Why is carrier testing important?

Parents who plan to have more children should consider carrier testing.

Carrier (genetic) testing can determine if you and your partner are both carriers for CF and help determine your chance of having a child with CF.

Other children or siblings may want to know if they are carriers eventually.

Carrier testing is available at Arkansas Children's Hospital or through your primary care doctor. Insurance may or may not cover testing.

To learn more about your status as a carrier or about carrier testing, talk with your healthcare provider or a genetic counselor.