## Children with CRMS should grow and develop normally.

You should expect your child to go to school, play sports, and do what all other children do.

Plan for your child to be an adult, go to college, have a successful career, and get married.

Your child's future children could have CF or CRMS if their mate is also a carrier for the CF gene.

Your child should be made aware of this risk when they are old enough to understand genetics and begin to plan for a family.

Males can have congenital absence of vas deferens resulting in infertility.

**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

# CFTR - Related Metabolic Syndrome

## What you need to know

Arkansas Children's
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#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 has CFTR-Related Metabolic syndrome (CRMS).

The diagnosis of CRMS does not mean your child has CF. However, there are several reasons why it is important to have regular check up with a CF specialist.

This brochure is to inform you about CRMS, 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.

## How do you get CRMS?

CRMS is genetic. This means it's inherited just like eye color, hair color, or height. To have CRMS, a person must inherit 2 copies of CF gene – one from each parent.

If both parents are CF carriers, this means they have one copy of a non-working CF gene, but do not have disease.

Each time two CF carriers have a child; their child has a 25% chance of having CRMS, a 25% of not having CRMS, and a 50% chance of having one CF gene or being carrier.

## What is CF and CRMS?

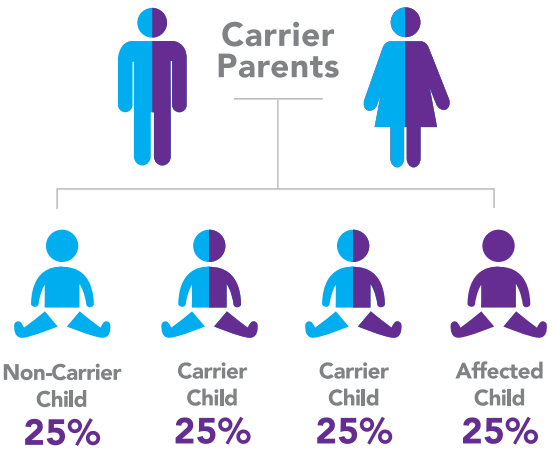
Cystic Fibrosis is an inherited disease that affects the respiratory, digestive, and reproductive systems.

A non-working gene and a protein (CFTR) causes the body to make thick, sticky mucus that can clog the lungs leading to infection and block the pancreas from making enzymes needed to digest and absorb food.

CF is diagnosed by a sweat test. Your child's sweat test had a mixed or inconclusive result. Your child has CRMS if:

- Their sweat test is higher than in normal children, but not high enough to mean your child has CF AND
- They have 1 or 2 CF genes which typically don't show CF symptoms

This means we can't say your child has CF, but could be at risk for having problems in the parts of the body affected by CF.




## What are CRMS symptoms?

Your child is likely to remain healthy. However, some people with CRMS develop problems in the airways, sinuses, intestines, or reproductive tract. You should notify a doctor of any of these symptoms:

- Cough or wheeze lasting more than 2 weeks
- Frequent lung infections
- Chronic sinusitis or nasal polyps
- Poor growth or no weight gain
- Frequent greasy, loose stools
- Constipation, stomach aches

## How do you treat CRMS?

There is no cure for CRMS. People with CRMS are likely to remain healthy and regular treatments are not needed unless symptoms occur. Some people with CRMS can become positive for a CF diagnosis later in life; however it is usually a milder form or non-classic CF.

## How do you stay healthy?

The best way to stay healthy is keep regular checkups with a CF specialist so any health changes or problems can be found early and treated quickly.

People with CRMS should:

- Avoid tobacco smoke
- Receive an annual flu vaccination
- Receive regular immunizations
- Keep regular checkups with a CF specialist at an accredited CF Care Center
- Inform your doctor of any new symptoms