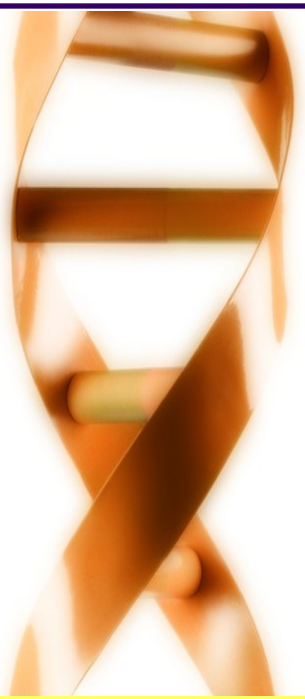
Quick Facts

- Cystic fibrosis (CF) is a life-long illness that affects breathing and digestion.
- CF "carriers" typically do not show any signs of CF.
- If both parents are carriers, there is a chance that their children could have CF.
- There is no cure for CF, but the earlier it is detect-ed, the earlier treatment can begin. Early treatment can lead to a longer and better quality of life.
- If neither of your parents are CF carriers, you will not be a carrier and do not need to be tested.



Questions? Please contact:

Cystic Fibrosis Carrier Testing

A question and answer guide to cystic fibrosis and carrier testing in the Hutterites.

What is cystic fibrosis?

Cystic fibrosis (CF) is a life-long illness that causes prob-lems with digestion and breathing. CF is usually diag-nosed within the first few years of life.

Cystic Fibrosis Carrier Testing in the Hutterites

What causes CF?

CF is genetic; that is, it is caused by changes in our genes. Genes are the inherited instructions that guide the growth, development and function of our bodies. Everyone has two copies of most genes, including the CF gene. Individuals with cystic fibrosis have genetic changes in both copies of their CF gene.

What is a carrier?

Carriers of CF have a change in only one copy of their CF gene. Because their other gene is unchanged, carriers are healthy and typically have no signs of the disease.

Could I be a carrier?

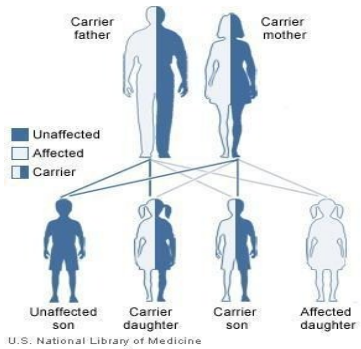
Yes. One in every 12 Hutterites (8%) is a carrier of a change in one of their CF genes. You could be a carrier even if nobody in your family has CF.

Why should I find out if I am a carrier?

It is helpful to know if you are a carrier even though it will not affect your own health. If both you and your spouse are carriers, you have a chance to have a child with CF.

What if my spouse and I are both carriers?

If both you and your spouse are carriers, then each of your children (or future children) has a 1 in 4 (25%) chance of inheriting the change from both parents and having CF.



In this figure, the parents are both carriers, each having one copy of a gene change for CF. The figure shows how there is a 1 in 4 (25%) chance of having a child with CF and a 3 in 4 (75%) chance of having an unaffected child (although they may carry one copy of the CF gene change like their parents). These chances apply to each pregnancy, regardless of the health status of your previous children.

What if only one parent is a carrier?

If only one parent is a carrier and the other is not, there is no chance of having a child with CF. There is the chance of having a child who is a carrier for CF, like the parent. Both you and your spouse have to be carriers to have a child with CF.

Can I prevent CF?

No. Because CF is genetic, there is nothing you can do to prevent the disease. There is also no cure for CF, but if it is found early, there are effective medicines and other treatments that can help a person with CF to live a longer and better quality of life.

How is carrier testing done?

CF carrier status can be determined by testing DNA from your blood or saliva. We may have a sample of your blood or saliva from a previous study, or we may ask you to provide another sample.

Can my family members be tested also?

We are offering free CF testing to Hutterites age 18 years and older who have participated in our previous studies. However, we can arrange for carrier testing for other Hutterites for a fee ($XXX/test). Doctors at the CF Center in XXXXX can also arrange for testing if your family members would like to be tested.