



**INFORMATION FOR PARENTS/GUARDIANS:
My Baby is a Cystic Fibrosis Carrier**

QUESTIONS

1. Did your baby have a positive newborn screen for cystic fibrosis? yes no
2. Did your baby have only one CF gene change (mutation) identified? yes no
3. Did your baby have a normal sweat chloride test? yes no

If you answered yes to **all** of the above questions, then this is the right pamphlet for you.

Your baby's newborn screening test showed an increased risk for cystic fibrosis (CF) but your baby's sweat test was normal. This means there is almost no chance that your baby has CF because it is very rare for a baby to have CF if the sweat test is normal. However, the testing did show that your baby is a CF carrier. This brochure explains what it means to be a CF carrier.

What is CF?

CF is an inherited (genetic) disease that causes thick mucus to build up in the lungs, digestive system and other organs. This leads to problems like frequent lung infections and problems gaining weight and growing. CF affects about 1 in 3,600 babies born in Ontario.

How does someone get CF?

CF is an inherited (genetic) disease caused by non-working genes. Genes are the instructions that tell our bodies how to grow and develop. We all have thousands of genes in every cell in our body. *Everyone* has two copies of the CF gene (called CFTR), one that we inherit from our mother and the other we inherit from our father.

Most people have two working copies of the CFTR gene. A CF carrier has one working copy of the CFTR gene and one non-working copy of the CFTR gene. **A CF carrier does not have, and will not develop, CF.** Most often, CF carriers are not aware that they carry a non-working CF gene as it does not cause any health problems. However, people who are CF carriers have an increased chance to have a child with CF. About 1 in 30 Ontarians is a CF carrier – that's about 400,000 healthy people in Ontario who are CF carriers.

In order for a person to actually have CF, they must have two non-working copies of the CF gene, one inherited from each parent.

How will being a carrier affect my child?

Your child is not expected to have CF related health problems because they are a CF carrier. No special treatment is needed. As your child grows up, talk with him/her about his/her CF carrier result. This information will be important for your child to know when he/she is planning their own family. His/her future partner can choose to have CF carrier testing so they know their chance to have a child with CF.

How can I find out if I am a CF carrier?

Since your baby is a CF carrier, this means that you, your partner, or both of you, are CF carriers too. Carrier testing for CF is an option for you and your partner. A blood test can usually tell if you are a CF carrier. A genetic counsellor can help you learn more about the genetics of CF, help you decide if you would like to have carrier testing done, and arrange the test for you.



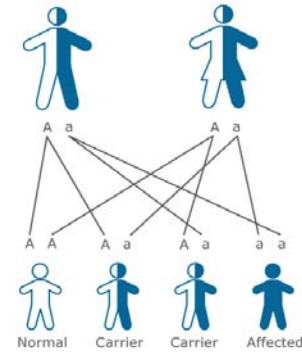


If we have more children in the future, could they have CF?

Most often, when a baby is found to be a CF carrier only one parent is a CF carrier and the chance to have a child with CF in the future is very low. There is a small chance that both parents are carriers. If both parents are carriers, there is a 1 in 4 (25%) chance to have a child with CF in any future pregnancy.

When both parents are CF carriers, each pregnancy they have has:

- A 1 in 4 (25%) chance of being affected with CF
- A 1 in 2 (50%) chance of being a CF carrier (but NOT affected with CF)
- A 1 in 4 (25%) chance of NOT being affected with CF and NOT being a CF carrier



When only one parent is a CF carrier, the chance of having a child with CF is very low.

How can I meet with a genetic counsellor?

If you would like an appointment with a genetic counsellor, ask your doctor to refer you to your local Genetics clinic. If you do not have a doctor, contact your local genetics clinic directly for more information.

What about my other children?

Carrier testing is usually not done in childhood as there is no medical benefit to knowing this information. When an individual is old enough to understand the information and make a decision for themselves, they can choose whether or not they want CF carrier testing. They may want to meet a genetic counsellor at that time.

Should my other relatives be tested?

Any blood relative of a CF carrier may also be a CF carrier. Your relatives may have questions about their chances to have a child with CF, too. A genetic counsellor can help your relatives learn more about CF carrier testing and arrange testing if they choose.

Where can I get more information?

For more information on newborn screening, please visit our website at www.newbornscreening.on.ca or talk to your local health care provider.

For more information on CF, please visit the Canadian Cystic Fibrosis Foundation website at www.cysticfibrosis.ca or call 1-800-378-CCFF (2233).

For more information about genetic counselling in your area, visit the Canadian Association of Genetic Counsellors' website at www.cagc-accg.ca.

NOTE TO PARENTS/GUARDIANS: This information is only applicable if your baby has been found to be a carrier of cystic fibrosis (CF). Please remember that this fact sheet was written for information purposes only. The fact sheet should not be a substitute for professional medical advice, diagnosis or treatment.

