

BC Newborn Screening Program

Information Sheet

My Baby is a Cystic Fibrosis (CF) Carrier *What does this mean for my baby, me and my family?*

Your baby's newborn screening test showed that he or she is a cystic fibrosis (CF) carrier. You may have heard about CF before. Your baby does **not** have CF.

Babies who are CF carriers are no more likely to get sick than any other baby. They do not need any special medical treatment.

What does it mean to be a CF carrier?

People's bodies are made up of tiny building blocks called cells. Inside the cells are tens of thousands of instructions called genes. Genes tell the body how to grow and develop. Two copies of each gene are present, one copy from the mother and one from the father.

Every person has changes (called *mutations*) in a few of their genes. Babies who are CF carriers have a change (mutation) in one copy of one of their genes (the CF gene). The other copy works well, which is why babies who are CF carriers are healthy. In British Columbia, about 1 in 25 babies are CF carriers – that means about 175,000 **healthy** people in BC are CF carriers.

Why is it important to understand that my baby is a CF carrier?

It is important to know so that you can tell your child later in life that he or she is a CF carrier. His or her future partner can then choose to have CF carrier testing. This information will tell them their chance to have a baby with CF.

Is there any chance my baby has CF even though the screen showed my baby was a CF carrier?

Almost all (more than 99%) babies that are found to be CF carriers by the newborn screening program will be healthy CF carriers. There is a very small chance (less than 1%) that any of these babies may have cystic fibrosis that is not picked up during screening. If you have concerns about your baby's health, please discuss these with your family doctor.

What does having a baby who is a CF carrier mean for me, my partner and for future pregnancies?

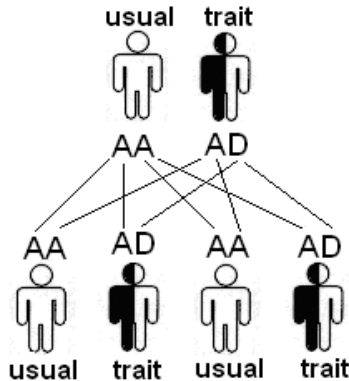
Since your baby is a CF carrier, this means that either you or your partner or both of you are CF carriers. In almost all cases, only one of you will be a CF carrier.

Most people do not know that they are CF carriers. Now that your baby is known to be a CF carrier, both you and your partner have the option of being tested. Testing involves a blood test.

IF ONLY ONE OF YOU IS A CF CARRIER, there is a 50% chance in every pregnancy to have a baby that is a CF carrier.

In the unlikely event that **BOTH OF YOU ARE CF CARRIERS**, in every pregnancy there is a:

- 1 in 4 (25%) chance to have a baby that is not a CF carrier and does not have CF.
- 1 in 2 (50%) chance to have a baby that is a CF carrier.
- 1 in 4 (25%) chance to have a baby that has CF.



If both of you are CF carriers and you become pregnant in the future, you will have the option of having your baby tested during pregnancy through prenatal diagnosis or after birth through newborn screening.

Should my other children be tested?

IF ONLY ONE OF YOU IS A CF CARRIER, it is recommended that carrier testing of your other children is delayed until after your child can make his or her own decision about whether to be tested.

In the unlikely scenario that **BOTH OF YOU ARE CF CARRIERS**, your other children may be tested to make sure they do not have CF. Your family doctor will help you decide the type of testing that would be best (a DNA test or a sweat test or both) and can arrange the testing.

Should my relatives be tested?

Any blood relative (for example, brother, sister, aunt or cousin) of a CF carrier may also be a CF carrier. Your relatives may have

questions about their chance of having a baby with CF, or may think that one of their children has CF. We suggest they talk to their family doctor who may offer them testing.

What is cystic fibrosis?

Cystic fibrosis is an inherited life-limiting disorder. It causes thick mucus to build up in the lungs, digestive system (and pancreas) and other organs. Most people with CF get chest infections. They also have problems digesting their food and, as a result, they may not gain weight as well as they should. CF affects about 1 in every 3,600 babies in BC.

Where can I get more information?

Talk to your family doctor. You may also call the CF Newborn Screening Team at 604-875-2623.

You may also want to think about talking to an expert about how family genes are passed on. This is called genetic counselling. You can also talk about your testing options and get more details on how these genes may affect other family members. You or your relatives can get genetic counselling through the Department of Medical Genetics at BC Children's and Women's Hospital or Vancouver Island Medical Genetics (at Victoria General Hospital). Ask your family doctor to refer you.

Information about the BC Newborn Screening Program can be found at www.newbornscreeningbc.ca.

Information about cystic fibrosis can be found at the Canadian Cystic Fibrosis Foundation website at www.cysticfibrosis.ca.

This fact sheet provides basic information only. It does not take the place of medical advice, diagnosis or treatment. Always talk to your health care provider about specific health concerns.